

**EXAMINING HOME-BASED CARE OF
CHRONICALLY/TERMINALLY ILL PERSONS BY FAMILY
CARE GIVERS AND THEIR INTERACTION WITH
PROFESSIONAL HEALTH CARE PROVIDERS,**

By

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I hereby certify that

Examining home-based care of chronically/terminally ill persons by family care givers and their interaction with professional health care providers.

Is my own work and all sources have been fully acknowledged in the text and in the bibliography.

A handwritten signature in black ink, appearing to read 'D. Mooka', written in a cursive style.

D. Mooka

SUMMARY**EXAMINING HOME-BASED CARE OF CHRONICALLY/
TERMINALLY ILL PERSONS BY FAMILY CARE GIVERS AND
THEIR INTERACTION WITH PROFESSIONAL HEALTH CARE
PROVIDERS.**

According to the Ministry of Health (1996:26), the most common chronic/terminal illnesses were cardiovascular disorders, diabetes, cancer, mental disorders, HIV/AIDS, tuberculosis and asthma. Long term treatment and care and the growing incidence of these conditions necessitated the introduction of home-based care (HBC). Consequently, family care givers play a major role in the provision of care to chronically/terminally ill patients and professional health care providers adopt a supervisory role.

This study examined the quality of home care services provided in Botswana. The availability and accessibility of home-based care services and resources have a direct bearing on the quality of home-based care delivery system. The researcher used systems theory as the conceptual framework for this study.

The study aimed to

- determine the accessibility and availability of home-based care services in Molepolole East
- investigate what the perspectives and experiences of family care givers, patients and professional health care providers of Botswana home-based care are
- determine the roles of professional health care providers, patients, and family care givers and their relationships in the context of home-based care

- identify the needs of chronically/terminally ill patients and family care givers
- determine the type of support given to family care givers and patients by professional health care providers and make recommendations for the improvement of home-based care
- develop a model to prepare family care givers

The research design combined quantitative and qualitative research methods. A sample of convenience was used to obtain information from patients' family care givers and professional health care providers. Interviews and questionnaires were used.

A proposed care giving preparedness model is presented to meet needs of the family care givers.

The study found that family care givers needs are neither known nor catered for by the professional health care provider. The family care givers were not adequately prepared before adopting the care-giving role.

It is recommended that

- The proposed preparedness care giving training model is considered for training of patients and family care givers before discharge and during HBC.
- Increase patients and family care givers decision-making.

KEY TERMS: Home based care, community care, chronically/terminally ill, care giving, preparedness model and partnership.

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LIST OF ABBREVIATION

- COCEPWA - coping centre for people living with HIV/AIDS
- FEW family welfare educator
- HBC - home-based care
- HIV/AIDS - human immune deficiency syndrome
- MPT - medium term plan
- NDP - national development plan
- NGO - non governmental organization
- PHC - primary health care
- UNICEF - United Nations International Children's Fund
- TB - Tuberculosis
- WHO -World Health Organization
- PLWA - people living with aids
- SADC - Southern African Development Community

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CHAPTER 1

BACKGROUND AND STATEMENT OF THE PROBLEM

1.1 INTRODUCTION AND BACKGROUND

Chronic/terminal illness is found among all age groups in any country, Lubkin and Larsen (1998:6) state that chronic illness is any condition that is prolonged, does not resolve spontaneously and is rarely cured completely, requires supervision and care over a long period and may require rehabilitation programmes. Cancer, diabetes mellitus, cardiovascular diseases, tuberculosis, asthma and mental disorders are most commonly diagnosed as chronic/terminal.

In Botswana, HIV/AIDS, chronic obstructive pulmonary diseases, arthritis, and neuro muscular disorders are listed as chronic illnesses (Ministry of Finance and Development Planning 1997:18; Kweneng District Annual Reports 1997:14; Scottish Livingstone Hospital Annual Report 1997:30).

The growing incidence of chronic/terminal illnesses in Botswana, puts a severe strain on the country's health care delivery system. According to the Ministry of Health (1996a: 30), HIV infections were the most common cause of death in the country. The majority of clients in home care are chronically/terminally ill adults and children. This state of affairs necessitated the introduction of home-based care (HBC) as a strategy of care for all patients with chronic/terminal conditions. McCormack and Ford (1999:42) state that chronic under-funding and inadequate resources from governments significantly contribute to inferior home care services.

1.1.2 Magnitude of chronic/terminal illness

In an address to the nation on 6 November 2000, the President of the Republic of Botswana Mr, Festus Mogae stated that the bed occupancy by people with HIV/AIDS was approximately 60%, and had prompted the government to allocate US \$6000000 to strengthen home-based care. The goal of home-based care was to reduce the pressure on hospitals. Moreover, the number of patients with tuberculosis (TB) and AIDS was escalating. He mentioned that these were not the only chronic/terminal diseases in Botswana but that he mentioned these because of their impact and magnitude, and adding that there was a gross shortage of personnel and equipment in health facilities.

The President pointed out the benefits of a home based-care programme for the chronically/terminally ill, such as assistance with basic household needs, foster care for AIDS orphans, food programmes and other support systems. The many patients requiring continuous care made it imperative for the government to introduce initiatives other than traditional institutional care to deal with the crisis.

1.1.3 "Gaborone Declaration, 2001"

In March 2001, the Gaborone Conference on the quality of home-based care was held with participants from Southern African Development Conference (SADC) countries, including Botswana. The Conference drafted the "Gaborone Declaration, 2001" which stated that a "strong political commitment is crucial to ensure an open supportive environment for effective home-based care programmes". The Conference stressed that home-based care should not be used as a way of decongesting hospitals, but rather as a strategic component in the continuum of care. At the conference it became clear that health care systems were not able to cope with the burden of hospitalising all chronically/terminally ill persons, hence the institution of home-based care (HBC).

1.1.4 Primary health care: a strategy for health care delivery

The government of Botswana adopted primary health care (PHC) as a strategy for health care delivery as identified at Alma Ata in 1978. This approach emphasises the provision of "essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford..." (WHO 1978:3). This implies that primary health care is an integral part of the overall social and economic development of a community. Health is not a commodity to be delivered to people by health personnel. It needs nurturing and care by individuals, families and communities themselves. Participation by communities is essential for them to achieve health. The home-based care programme demonstrates the principle of care in the hands of communities and their involvement in making decisions for health care delivery.

In Botswana, the primary health care approach employs mechanisms to have chronically/terminally ill patients cared for by relatives or family members at home and given support at various levels of the health care system. According to the Ministry of Finance Development Planning (1997-2003:480-481) Botswana government makes provision for improving the quality of health care, stating, that "the goal of the Ministry of Health is to improve the efficiency and effectiveness of health care delivery, to ensure equitable distribution of services; to improve quality of care ... to strengthen primary health care programmes".

1.1.5 Health of family care givers *

The increasing number of chronically/terminally ill since in the early 1990s has made home-based care, which relies on family caregivers imperative. Home-based care can be very stressful for the family care giver especially when it is

prolonged over months and years. According to Peters (1998:26), the actual act of providing care involves many changes for both the family care giver and the patient, in conducting the day-to-day activities of their lives. The life style of the family care giver might have to be adjusted to include the needs of the patient. As a result of the chronic/terminal illness, the patient might experience limitations and restraint; they may not be able to do things for themselves and become dependent partially or solely on the family care givers. Family care givers' own peculiar health needs may interfere with care giving at home (Lubkin & Larsen 1998:93). In some cases family care givers have chronic health problems themselves but they are expected to look after their chronically/terminally ill relatives. The issue is whether family care givers are able to render quality care, given their own ill-health status. Family care givers with health problems themselves require more support in giving care to the chronically/terminally ill. Community health nurses should provide information about the difficulties and needs of the family care givers so that adequate and appropriate action is taken and impossible situations avoided (Newman1991: 10). In a study in Kgatlang district on needs of care givers Ngwako (1994:28) found that family care givers lacked support such as home visits by professionals health care providers and that home-based care was not well co-ordinated from hospital to community. Lubkin & Payne (1998:259) state that women are especially vulnerable to chronic conditions because of their lack of support in bearing and raising children in single female-parent families and caring for the elderly.

Woo (2000:9) points out that providing this support can have detrimental effects on family care givers' emotional, physical and social well-being. Robinson and Austin (1998:58) found that caring for a chronically/terminally ill persons in the home impacted on the family care givers in the form of fatigue, stress and strain.

Most family care givers are women and in many cases their social and occupational health has suffered. Before anyone can be assigned the role of family care giver the following factors need to be considered:

- the family care giver's own health
- ability to function
- knowledge, expectations, other roles, responsibilities, and sources of help/support.

Lubkin and Payne (1998:259-260) state that the quality of home-based care is of grave concern because of the growth in home care services and lack of adequate resources.

Policy makers need to develop programmes that are sensitive to the needs of family care givers and the problems that they encounter on a daily basis as they strive to render the quality of care expected. Alternative strategies should be made available in cases where family care givers are not willing or able to accept home- based care patients.

1.1.6 Home-based care in the African context

The concept of home-based care in the African context has its roots in family members providing essential care to the chronically/terminally ill. The complex nature of chronic illness seriously affects the patients and their family care givers in the home. Today family values have disintegrated, family violence is a common occurrence and, in some instances, family members consider the chronically/terminally ill a burden.

The 1996 Annual Report of Nyangabwe Hospital in Francistown (1996:5) cited the following problems in home-based care in the northeast districts:

- Patient rejection by family members at the time of discharge made the transition from hospital to community difficult.
- A lack of extended families in town necessitated using maids as family care givers, which resulted in the neglect of the patients.
- There was a shortage of basic home-based care commodities.

In its study of poverty alleviation as part of the national development plan, the Ministry of Finance and Development Planning (1997:72) found that 75 % of home-based care was performed by women. Furthermore, nearly a quarter of family care givers were spouses, while a third were 65 years and over.

Philipp and Black (1998:514-515) point out the financial impact of chronic illness. In its national development plan 8, the Ministry of Finance and Development Planning (1998) pointed out that most family care givers are women who are usually not employed. In Botswana, although some family care givers have the desire to look after their loved ones, most continue to struggle with poverty, with low or no income and very little food. Furthermore, the Ministry of Health (1997- 2002:22) emphasises the financial burden of providing home-based care and that "the major burden of care will fall on the elderly, the woman, and the girl child in the household ... the epidemic will also have a cancelling effect on the old age pension scheme when it is used to support HIV/AIDS - related household expenditure".

Xu and Hu (1996:358) point out that ninety percent of all health care of the chronically/terminally ill is given on a self-or lay care basis. Woo (2000:157) found that chronically/terminally ill people usually strive to achieve normalization as soon as possible. They build a wealth of knowledge about the disease, accepting responsibility for regimens such as self-medication, dressings, blood pressure monitoring and diet.

According to Ministry of Health (2000c: 15) many family care givers lack professional help and economic support, which could ameliorate some of their problems. The main reasons given for care giver's rejection of official help or failure to obtain it included complexity, variation and anomalies in the organisation and administration of services.

The Botswana *Daily News* (20 June 2001:2) reported family care givers' concern over the quality of services in home-based care. Family care givers voiced their concern in an HIV/AIDS Workshop, complaining that shopkeepers at times gave them rotten food or refused to supply them with food, saying the district council had not paid them the money that the government allocated for people in home-based care. The shopkeepers designated to supply social welfare food blamed family care givers for not collecting the food on time. Consequently, home-based care patients who needed food were not getting it at the expected time. This situation alone indicated that poor quality service was delivered in home-based care.

1.1.7. Preparation for home based care

Chronically/terminally ill patients are most often discharged into the home-based care of the relatives whom they were staying with before being admitted to hospital. How well prepared the family members are who take up this grave responsibility is an area of concern. Although many long-term sick persons can cope with their illnesses and intermittent medical and/or nursing interventions, the majority are highly dependent, thus making it mandatory for them to live with others.

Munodawafa and Ncube (1997:9) state that "the success of a home-based care programme depends on how the health professionals in the hospital setting

prepare patients, relatives as well as significant others on the planned discharge". Professional health care providers at the stage of discharge planning for home-based care should conduct a comprehensive health assessment of the family into which the patient is to be discharged.

An assessment of both the patient and family care givers' needs determines whether the family care givers have the ability to take up the care-giving role or not. A comprehensive assessment is the cornerstone of good practice in the health and social care of chronically/terminally ill patients including their family care givers. The quality of that assessment and subsequent action is a key factor in determining the outcome of home care.

1.1.8 Challenges of Botswana home-based care strategy

In Botswana the home-based care programme has developed checklists, guidelines, manuals and other measures to ensure quality of service in home-based care. The Ministry of Health (2000d: 4) indicates however that despite these measures, the health care system is inundated with reports of dissatisfaction with the quality of health service delivered. The challenges facing the implementation of the community home-based care programme in Botswana include

- improving the quality of care
- increasing access by clients to home and community care
- the provision of social support to clients
- sustaining the level of participation and commitment by volunteers and support groups.

In its report on monitoring visits to the districts to evaluate home-based care activities, the Ministry of Health (2000a: 15) noted a lack of collaboration

between the various health sectors in Botswana. Chronically/terminally ill patients were frequently discharged into the community before the nurses and family welfare educators were informed about them. The professional health care providers found out about the discharged home- based care patients through the grapevine.

1.1.9 Health assessment of family care givers

The Ministry of Health's training manual, modules on home-based care for training of trainers (2000c: 10) states clearly that assessment of clients' health status and needs for care, counselling and support is necessary in home care nursing. No mention is made of assessing the family care giver's needs prior to adopting home- based care. In situations where no assessment was made, the family care givers might prove unable to render care at the expected level.

Discharging patients to family members does not make those members competent to render care if they are incompetent. Miller (1991:4) stresses the importance of an assessment at discharge, stating, "consider the family care giver's ability to adequately perform the care giving services, or, conversely, consider the potential of abuse and neglect if a patient were inappropriately placed in a dysfunctional family".

Carpenter (1998:12) points out that the recognition of chronic illness as a major health problem is attributed to a change in philosophy about health, chronic illness, disability and the roles of health care professionals, family care givers and clients in management of chronic illness.

1.1.10 Nurses' role in home- based care*

Caring for chronically/terminally ill patients makes great demands on professional health care providers and family care givers. Usually nurses play a major role in helping families bear the burden of living with persons who are chronically/terminally ill. One of the main aspects of being a nurse, then, is interacting with the family, which should result in a close relationship between the professional health care providers; the patient and the family care givers. At times, however, this interaction does not happen.

In a study on hospitals in the Northern part of Botswana Shabane (1993:20), found that the quality of care in Botswana hospitals was perceived as poor by both patients and nurses, the reasons given for this were shortage of manpower and inadequate equipment

The specific roles of these nurses should be reviewed to ascertain how they would ease the burden of care giving for family care givers since family care givers care for patients directly on a 24-hour basis. Trained nurses in Botswana only conducted home visits on certain days of the week.

The policy on home-based care needs to be clarified to meet the needs of patients, family care givers and professional health care providers directly. Few community health nurses work in the community as many of them are placed in administrative posts at district headquarters.

Adequate numbers of qualified nurses are needed in every community to realistically assess the needs of patients and family care givers who need support. Assessing the needs of family care givers should be the concern of

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community health nurses who should be at the forefront in caring for the chronically/terminally ill in the community. Quality home-based care depends on their qualification as they supervise the care given and do referrals when necessary.

1.1.11 Users/receivers of health care services

In this study, family care givers, and patients were regarded as users/receivers of health care services if they themselves were chronically/terminally ill and on treatment. The family care givers were considered providers of care to patients for the time that they were looking after a chronically/terminally ill relative. The family care giver might not have had prior knowledge or experience of looking after a chronically/terminally ill relative. This would make the type of care given haphazard and poor hence the need for increased support from professional health care providers.

1.1.12 Botswana and HIV/AIDS

Many people die from retroviral infection and congestive cardiac failure. In its 1997 annual report the Scottish Livingstone Hospital (1997:10) in the Molepolole village reported that 90% of the patients discharged to home care were diagnosed with HIV/AIDS related diseases and were on palliative treatment. Not all chronically/terminally ill people are totally dependent. The major prevention strategies should aim at preventing them from becoming either disabled or a handicapped.

According to the Ministry of Labour and home Affairs (1997:9), the main aim is for all Batswana to have access to good quality health care services within reasonable travelling distances by the year 2016. A further objective is for people suffering from HIV/AIDS and AIDS- related illnesses to have good

quality treatment in health care facilities, communities or the workplace so that they continue to live full and productive lives for as long as possible. Since all other long-term illnesses are included, these objectives are expected to become a reality in the health care system. The care that chronically/terminally ill patients receive at home should be of a high quality.

In a study in Maun on how it feels like to be diagnosed with HIV/AIDS in Botswana, Ditirwa (1994:2) states that in developing countries people die early because they fail to receive adequate care. These people hide their diagnosis and there is little support from either friends or family.

Although the Botswana government advocates home-based care, there is a stigma attached to chronically/terminally illness, especially HIV/AIDS and home-based care.

In order to improve health care services, it was necessary to know how Botswana's concept of caring fits into what is generally described as care giving. There was a need to examine how traditional people handled their ill relatives' needs, whether the chronically/terminally ill were given love and attention, and whether family care givers had the knowledge to care for people with infectious diseases. The reason adults get infected with diseases like HIV/AIDS and TB is probably their lack of knowledge about the mode of transmission and preventive measures. While patients are referred to home care there should be a common understanding of what the family must expect. The family care givers must know how to protect themselves from infectious diseases. In Botswana, family care givers carry a heavy burden some end up with infectious diseases themselves through ignorance of the major issues of home nursing.

1.1.13 Services in home - based care

In Botswana, home-based care includes direct patient care, provision of social services, counselling and psycho-social support to clients by family care givers and professional health care providers. According to Molosiwa (2000:3), there are more than 8000 people in home-based care in Botswana. As a result, providing care for a chronically/terminally ill relative or significant other at home is becoming increasingly common in Botswana.

Miller (1991:5) states that quality in home based care implies to eliminate "fragmentation and duplication of patient services; assure continuity of services; ... closely monitor all aspects of patient care; ... observe changes in condition or unmet need; ... afford the patient and family the security of after hour and weekend services... facilitate a close relationship with the patient; to order the most appropriate and cost effective patient care and to enhance family support". Accordingly this study examined the quality of home-based care in Botswana.

This study focused on the home-based care perceptions and experiences of patients, family care givers and professional health care providers. In home-based care the family care givers render care to family members. The researcher examined the availability and accessibility of home-based care resources. Professional health care providers can assure the quality of home-based care only when adequate resources are available and accessible in right quantities at the right time to the right people.

1.1.14 Policy on home-based care *

According to the Ministry of Health (2000d: 2), the home-based care policy in

Botswana was introduced in 1992 mainly to look after destitutes, the disabled and HIV/AIDS patients. Other chronic illnesses such as diabetes, asthma, hypertension, stroke, cardiovascular disease, mental disorders, chronic obstructive disease, arthritis, and neuromuscular disorders, were incorporated later.

The home-based care policy introduced in 1992 aroused concern and debate among health professionals and the public in Botswana. Some maintained that the government's intention was to shift the entire responsibility for care of the chronically/terminally ill from the state to the individuals and their relatives. Others welcomed this change in health care as something that was culturally acceptable and had always existed in African communities. The Botswana government's primary health care policy emphasizes equity, intersectoral collaboration and community involvement. The basic objective of the national health policy is access to essential health care regardless of financial and social status of the individuals.

The health care policy provides for an equitable distribution of health resources. This indicates that the quality of home care should be comparable to hospital services. Moreover, the services and resources for home-based care must be available and accessible to all who need them.

In this study the researcher wished to establish whether the quality of home-based care in Botswana was of an acceptable standard.

1.1.15 Role of non-governmental organisations (NGO's) in chronic/terminal illness

A report in *Mmegi* (18-24 May 2001: 2), cited Ms Helen Ditsebe-Mhome, the Director of the AIDS Coping Centre for People Living with HIV/AIDS (COCEPWA) as stating that whilst the government was proud of the work at the Centre, the support received from government was inadequate. The Centre looked after hundreds of people who did not have food and needed blankets as a matter of urgency. Apart from the need for a vehicle the organization desperately needed funds. A situation like this denoted starvation amidst plenty. The question was what had gone wrong if the government was spending a lot on home-based care yet there were still many who were in great need.

According to Foley (in Miller 1991:1), the greatest challenge to home care was the availability of services. Home care was becoming capacity constrained, personnel were becoming scarce and unit cost was increasing. Serving the right people at the right time with the right service is difficult, unless changes were initiated in the home-care delivery system.

The public and non-governmental organizations (NGOs) expressed dissatisfaction with the way home-based care operated. The Botswana *Gazette* (9th May 2000: 3) reported Ms Boitumelo Leburu, Chairman of the Gabane Home-Based Care project as saying that "problems arise because Family Welfare Educators (FWE) who are involved in home-based care do not have a clear job description. There is nothing compelling them to walk to patients' homes to go and check on them, and this at times creates a problem for us. It is high time qualified officers who are permanently employed run home-based care. There is so much we hear about money available for home-based care projects but the mystery is how to get it. We continue to struggle". The Gabane Home-Based Care Project also started an orphanage for children whose parents had died from HIV/AIDS.

O'Neill (1997:35) found that junior nurses lacked the experience to know when to involve patients in decision making. The Botswana *Daily News* (20 June 2001: 4) reported that international organizations were keen to participate in improving the health of the Batswana. For example, renowned reggae music group, UB40, from the United Kingdom promised Botswana the net proceeds from a concert to celebrate their birthday, and the United Nations Development Programme (UNDP) had already identified projects to benefit Botswana, including ones involving commercial sex workers, HIV/AIDS, orphans, people living with AIDS (PLWA) and home-based care.

1.2 CLARIFICATION OF HOME BASED CARE

1.2.1 Caring

According to Powel-Cope (1994:325) caring is a nurturing way of relating to a person toward whom one feels a personal sense of commitment. Caring is equally organisational and physical as well as emotional labour. In caring, emotional involvement features very high. This would mean then, that caring is only possible where the patient and family care giver has the necessary support available and their needs as individuals are met.

According to Morse, Solberg, Neander Bottorff and Johnson (1990:5), there are five perspectives of caring, namely as

- a human trait
- a moral imperative or ideal
- an interpersonal relationship
- a therapeutic interaction
- an effect

Pender (1996:258) maintains that nurses and patients' perspectives are different, because nurses focus mainly on their psychosocial skills, while patients focus on nurses' professional skill and competence.

According to Munodawafa and Ncube (1997:30) socio-cultural issues should be considered in home-based care and health workers must learn about the clients' cultural practices to avoid ethnocentrism: "A significant number of health workers are foreigners ... the population of Botswana is made up of subcultures which are represented in various divisions of the health care system. Home based care in Botswana is being implemented in a pluralistic society in which members are of diverse ethnic, racial, religious and social groups, maintain independent life styles and adhere to certain values within the confines of a common civilization".

Swanson (1991:162) outlines five aspects of caring:

- knowing: striving to understand an event and its meaning for the patients
- being with: being emotionally present with the patients
- doing for: doing for the patients in a way they prefer
- enabling: facilitating the patients' passage through life transactions and unfamiliar events
- maintaining belief: believing with meaning in the patients' capacity to get through and face the future.

The nurse's role in caring for long- or short- term chronic/terminal ill patients is complex. The nurse needs to identify a care plan for patients' physical, emotional, social and spiritual needs as well as to provide support and advice to the family care givers and social groups.

In this study, caring means the provision of home health care which includes specific caring characteristics such as good mood, understanding, genuineness, patience, respect, giving emotional support, listening, giving hope, spending time, physical support, giving advice/information and co-ordinating services (McQueen 1997:334). For family care givers to exhibit such characteristics, the environment must be supportive to home care giving.

1.2.2 Community participation in home-based care

It should be noted that participation in care giving constitutes a radical change in both health care policies/strategies and the role of the health practitioner.

According to Cahill (1998:120), "participation implies that one becomes actively involved in the nature of something with others and that participation is getting involved in decision making or the process of delivery or evaluation of services and being consulted on an issue or own care." To ensure community participation the major key players take an active role in decisions about their own care needs (Dreyer, Hattingh, & Lock 1997:134).

McKinnon (1997:114) states that "allowing for decision making on the part of the individual client in conjunction with his/her family assists in the development of realistic goals. Clients must be active participants in the planning and implementation of care to ensure improved outcomes".

Community participation may include compliance and cooperation with what is provided by the system. Not letting people share in decisions, power, and responsibility for health implies a lack of participation. The question for Botswana is how much or to what extent patients and family care givers participate in issues of home based care and own health care. Patients need to actively participate in decisions on their care for they have valuable experience that professional health care providers can learn from (Methost-de Biel 1998: 2).

In this study, the researcher investigated chronically/terminally ill patients' and family care givers' level of participation in their own health care and decisions in home-based care in Botswana. True participation is only possible when the means to bring about the desired results are in the hands of the communities.

King (1996:264) states that community participation increases the nurses' responsibility in assisting communities to accept responsibility for their own health. At times nurses see this situation as a problem as they are reluctant to let communities make their own decisions.

1.3 ^INTERPERSONAL RELATIONSHIPS AND ATTITUDES IN HOME-BASED CARE

1.3.1 Nursing as a relationship

Nursing is a relationship in which two or more people are involved in a transaction. It is also important to consider how people influence each other. The key dimension of nursing is the relationship between the nurse and the patient. Patients are assessed, advised, supported, informed, or cared for in a person-to-person relationship. The relationship between nurse, patient and/or family care giver is decisive in the outcome of care. Nurses and patients interact in order to set mutual goals and determine the means to achieve those goals (George 1995:222).

Home-based care is multidisciplinary and nurses play a pivotal role as they are more in contact with chronically /terminally ill patients than any other person. The health care system in Botswana is such that nurses, who are the ideal people to assess and educate patients and families in the community, provide three-quarters of the health care services. For this reason, it was important to know the nurses' attitudes towards the chronic and terminal ill and their family care givers.

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1.3.2 Nurses' attitudes

Negative attitudes of nurses and other professional health care providers towards cancer patients had a negative effect on patient care. The health care providers assumed poorer prognosis for cancer patients than those with other life-threatening diseases. In a study in the southern part of Botswana, Masalila (1993:17) found that the elderly rural residents perceived nurses negatively as unpleasant to patients, and not careful and gentle when taking care of patients.

To prevent these perceptions in case of HBC and to ensure that home based care is of high standard, care should become more client focused and nurses should be committed to assist and support care givers. This necessitates the involvement of clients in evaluating health care service delivery. Evaluating care from the clients' perspective would indicate the quality and outcome of home-based care. Clients should play a prominent role in health care delivery.

1.3.3 Family care givers attitudes

Family care givers attitudes as well as professional health care providers attitudes influenced the quality of care rendered to chronically/terminally ill patients. Not all relatives and patients want to take part in patient care; some are negative towards participation. All patients' relatives should perhaps not be expected to willingly accept the care-giving role.

The Scottish Livingstone Hospital in Molepolole (1997:6) reported that family care givers were reluctant to keep very ill persons at home; they preferred them to be hospitalized despite counselling of relatives. What exactly this counselling comprised and what the family care givers' perceptions of the interaction with these professional health care providers were needed to be determined. This

interaction determines the family care givers' contributions to decisions on the patients's discharge and care.

The Scottish Livingstone Hospital (1997:7) reported further that there was a lack of family support for chronically/ terminally ill patients, especially those with mental illness, and this accounted for relapses. There is a stigma attached to mental disorders in the Botswana community.

Some family care givers find themselves compelled by circumstances beyond their control to provide home-based care. In a study addressing factors associated with hospitalization at Lobatse referral mental hospital in Southern district, Botswana, Monggae (1993:3) found that communities lacked knowledge on the behavioural changes and management of psychiatric patients. The illness was stigmatised and relatives would rather have family members spend a lifetime in a hospital than care for them at home.

Ideally, community home-based care should enable chronically/terminally ill patients to be cared for in their own homes, make their own choices and live their lives with the acceptance of the local community. In Botswana there is a growing population of chronic mental patients requiring long-term care. Community mental health care implies a reliance on informal support networks, which cannot always be guaranteed.

1.4 DEFINITION OF TERMS

The following terms are used in this study.

1.4.1 Patient/client

Patient or client refers to the person who is ill, and anyone in need of help from a professional health care provider. The help is offered in the context of a relationship.

In this case the client or patient is in need of home-based care.

1.4.2 Chronic illness

According to Mattson (in Coyne 1997:121) chronic illness refers to a disorder with a protracted course that can be progressive and fatal or associated with a relatively normal life span despite impaired physical and mental functioning. Such a disease shows periods of acute exacerbations requiring intensive medical attention. Chronic illnesses include cancer, diabetes mellitus, cardiovascular diseases, tuberculosis, asthma and mental disorders. In Botswana, HIV/AIDS, chronic obstructive pulmonary diseases, arthritis, and neuromuscular disorders are also listed as chronic illnesses.

1.4.3 Home- based care

The ministry of Health (1996:3) defines home-based care as "care given to people in their own environment by families ... by skilled ... officers and communities ...the target group for this programme is any person with HIV related disease/AIDS ... including other chronically/terminally ill patients".

Home-based care is care given to clients outside the institution, and incorporates considerations of chronic and transitional services influencing health care delivery of all ill persons, especially the chronically/terminally ill.

Home-based care encompasses the provision of services by family members, significant others or trained community members in the home to deal with and meet the physical, emotional, social, and spiritual needs of chronically/terminally ill patients. Although some people prefer to die in hospitals, home care is becoming the alternative for terminally ill patients. Lubkin and White (1998:69) state that 50% of the terminally ill patients prefer to die at home.

1.4.4 Family care givers

For the purposes of this study "family" refers to any significant relationships such as friends, spouses, relatives or life partners, lovers or neighbours. Thus families are social systems in which members have ties to each other, are interdependent, have a common history, and share goals.

Kumlien and Axelsson (2000:90) state that the care giving role falls on one person, usually a spouse or an adult child. This pattern is more or less what is found in Botswana with its culture of the extended family.

1.4.5 Professional health care provider

In this study, professional health care providers include physicians, nurses, social workers, family welfare educators or any other professional health care provider of the patient or family care giver interacted with during the chronic/terminal illness.

1.4.6 Health team and teamwork

According to O' Neill and Rodway (1998:59), "effective teamwork requires mutual understanding of the roles of each team member. General practitioners must maintain overall responsibility for medical care of patients at home". They go on to say that general practitioners are in a good position to understand the past and the future, which is essential in the solution of current problems. District nurses play a vital role in rendering nursing care, while it is the responsibility of social workers to assess a "package of care", appropriate for nursing care. Clinical psychologists trained in family therapy may be used for referral of complex problems.

1.5 QUALITY IN HEALTH CARE

Biggs (1996:305) defines quality in home-based care as "meeting or exceeding the customer's needs and fulfilling his/her expectations". According to Ellis and Whittington (1993:23), it is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge".

Quality is assured in health care through establishing professional standards and monitoring performance by patients, family care givers and professional health care providers for the benefit of communities. Dreyer, Hattingh and Lock (1997:32) state that "a community health nurse must be aware of standards and criteria established for quality community health care ... realise her responsibilities in ensuring that the highest standard is achieved ... through regular inspection, supervision and evaluation of services rendered". When these requirements are not met, care cannot be considered to be of quality. Dreyer et al (1997:30) go on to say, "one of the most important management functions of a community health nurse is to supervise the delivery of health care in home care on a continuous basis to ensure quality of services".

Family caregivers need material and emotional support. Support for family care givers is frequently not adequate because health professionals do not offer a service, or fail to respond to or act on a referral, or arrange for services on a kinship basis.

According to the Ministry of Health (1995a: 11), "the districts or city councils shall be responsible for planning, evaluating, and providing basic services for persons residing in their respective areas in accordance with government policy and any guidelines ... issued by the ministry regarding such services including the following as a minimum:

- health promotion and avoidance of ill health
- health education
- environmental health
- disease prevention
- care of vulnerable groups
- rehabilitation of the disabled".

The home-based care service should provide people with what they need and do so at the lowest cost. Quality is achieved through adhering to set standards and criteria.

1.6 STATEMENT OF THE PROBLEM

The focus in this study is on the provision of quality home- based care (HBC) by family care givers supported by professional health care providers.

The problems in providing such a service are many and complex and revolve around the needs of a growing pool of chronically/terminally ill persons in

Botswana as well as the needs of the family care givers who are at times also chronically ill. Care givers often experience difficulties with availability or maldistribution of resources; negative social relationships; lack of support from the professional health care providers; poor planning and evaluation of services and negative perceptions about HBC.

In Botswana HBC as a system relies primarily on family care givers yet there are no well-developed systems to support these care givers. HBC could be very stressful for the family care givers especially when it is prolonged over many months or even years. Furthermore HBC was initially designed to cater for the increasing numbers of HIV/AIDS patients, not for other people like the chronically/terminally ill.

The HBC programme does not provide directly for the needs of family care givers although their needs may have a great impact on the quality of services provided patients and families are often not informed about the health situation of the patient and they are not properly prepared or consulted before the patient is discharged into the HBC system with the result that family care givers are unable to cope and services are provided haphazardly.

The researcher conducted this study in Molepolole sub-district of Kweneng east between 1996 and 2001 because a large number of chronically/terminally ill people in this area indicated a serious need for HBC.

1.7 SIGNIFICANCE OF THE STUDY

According to the Ministry of Health (1996a: 28), Botswana had a large chronically/terminally ill population in 1996. In the Kweneng East district the

major chronic health problems were cardiovascular disorders, neurological, respiratory, endocrine, reproductive and immune system disorders. As these diseases progress, patients become more dependent on family, friends, and professional health care providers to look after them in home-based care.

Tables 1.1, 1.2, 1.3, and 1.4 below represent the state of chronic/terminal health problems in Kweneng East of Botswana in 1996 in terms of out-patients treated, the major causes of in-patient morbidity, in-patient discharges and institutional deaths related to various diseases according to the 1996 health statistics.

TABLE 1.1 Number of outpatients seen according to age

CONDITION	AGE IN YEARS	NUMBER
Blood pressure	5-14	931
	15-44	70,344
	45	122,910
cardio-vascular	5-14	172
	15-44	3,395
	45	5,445
Mental Disorders	5-14	739
	15-44	11,731
	45	5,100
Asthma	5-14	2,095
	15-44	19,516
	45	8,931
Psychiatric outpatient attendance		35,098

TABLE 1.2 Major causes of in-patient morbidity

CONDITION	MALE	FEMALE
Hypertensive diseases	729	1,850
Bronchitis, chronic unspecified, Emphysema and asthma	749	1,640
HIVAIDS	749	1,640
Pulmonary tuberculosis	323	199
Pneumonia	300	291

TABLE 1.3 In- patient discharges

CONDITION	NUMBER
Malignancies of all types	2,618
Malignant neoplasts of Genito-urinal organs	422
Malignant neoplasts of bone and Connective tissue	282
Malignant neoplasts of digestive system	332
Diabetes mellitus	785
HIV/AIDS	1,235
Mental disorders	1,211
Cerebro vascular diseases	350
Bronchitis, chronic and unspecified, emphysema and asthma	1,640

TABLE 1.4 Institutional deaths related to various diseases

CONDITION	NUMBER
Tuberculosis	587
Malignant neoplasts of digestive organs	109
HIV/AIDS	527
Mental Disorders	11
Pulmonary Circulation and heart diseases	246
Pneumonia	591
Diabetes	46
Bronchitis, chronic and unspecified, emphysema and asthma	22
respiratory disease	711

Source: Ministry of Health (1996a: 26-27)

There is a lack of research in Botswana on patients, family care givers and professional health care providers' perceptions of home care and satisfaction with the services provided. Therefore, the researcher wished to obtain basic data through this study for use in developing future home-based care programmes as well as an education and training programme sensitive and relevant to the needs of patients and family care givers. Such programmes would assist in making home-based care resources, such as personnel, finance and materials, available and accessible to patients, family care givers, and professional health care providers at the right time and in the right place.

1.8 OBJECTIVES OF THE STUDY

The objectives of the study were to

- determine the accessibility and availability of home-based care services in Molepolole East
- investigate what the perspectives and experiences of family care givers, patients and professional health care providers of Botswana home-based care are
- determine the roles of professional health care providers, patients, and care givers and their relationships in the context of home-based care
- identify the needs of chronically/terminally ill patients and family care givers
- determine the type of support given to family care givers and patients by professional health care providers and make recommendations for the improvement of home-based care
- develop a model to prepare family care givers

1.9 RESEARCH DESIGN

The study used descriptive triangulation, which combined quantitative and qualitative research methods simultaneously. The purpose of using triangulation was to provide a basis for convergence of ideas. By using multiple methods the researcher hoped to rule out error. The qualitative methods described affective aspects of the domain while the quantitative methods measured other variables.

1.10 SAMPLING AND POPULATION TECHNIQUES

A sample of convenience was used to obtain information from patients, family care givers and professional health care providers because they play a vital role in determining the quality of care. The family care givers consisted of spouses, relatives, friends, neighbours, or significant others, male or female. The

participants described their perceptions and experience of caring for the chronically/terminally ill persons and home-based care.

1.10 DATA COLLECTION

The researcher used interviews and questionnaires, as data collection techniques as there is a higher response to interviews than questionnaires thus leading to a more representative sample. The questionnaire was compiled to cover the respondents' major areas of content to assess clients' biographic details, perceptions and experiences of their problems, use of and satisfaction with home care, and general health status. The researcher used both open-ended and closed questions on home base care to compare and facilitate analysis.

1.12 FORMAT OF THE STUDY

Chapter 1 presents the background to the problems, the statement of the problem and the objectives of the study. Some terms used in the study are defined and the quality of home-based care is discussed. Chapter 2 discusses the approach to the study, using the systems theory. Chapter 3 covers the literature review. The research methodology is discussed in chapter 4, including data-collection techniques. Chapter 5 covers the data analysis and interpretation. Chapter 6 discusses the proposed model to prepare family care givers its major concepts, propositions and their relationships. Chapter 7 concludes the study and makes recommendations for further study.

1.13 CONCLUSION

This chapter discussed the problem of caring for ever-increasing numbers of chronically/terminally ill patients at home in Botswana. The most common chronic/terminal illnesses in Botswana are cardiovascular disorders, diabetes,

CHAPTER 2

APPROACH TO THE STUDY

2.1 INTRODUCTION

The topic, purpose and significance of the current study were discussed in chapter 1. The researcher adopted a systems approach to the study.

A system is a group of related elements organized for a purpose. General systems theory (GST) is a general science of organization and wholeness. It is commonly agreed to have been founded by von Bertalanffy (Bullock and Stallybrass 1979:273). Among the first people to utilize systems thinking in nursing was Imogene King, who developed a theory for nursing in 1981. In her systems framework for nursing, King (1995) views family members as complex subsystems interacting with the environment. Health care systems are open, and professional health care providers are subsystems that interact with the family members and the chronically/terminally ill. This approach emphasises complex family interactions between personal, interpersonal, and social systems. In the current study, "family" embraces not only blood relatives but all significant others involved in care giving (see chapter 1 section 1.10.) The systems approach views the patient and the family care giver holistically as a whole system with interdependent parts. The system and its parts have structure and functional components.

2.2 THEORETICAL FRAMEWORK

According to Stanhope and Lancaster (2000:206) it is important to have a theoretical framework in research. First, it gives a basis for making decisions and establishing priorities. Secondly, this gives the researcher an opportunity to examine programmes systematically for deficiencies and deal with potential problems. Thirdly, it serves to explain why things are done in a particular way.

A systems framework for nursing helps to define its parameters and identify its unique focus. For this reason, the researcher used the Kings theory to examine the quality, accessibility and availability of home-based care for the chronically/terminally ill in Molepolole East to determine deficiencies in its implementation.

2.3 CHARACTERISTICS OF A SYSTEM

Pearson and Vaughan (1990:27) list the following characteristics of systems:

- Systems seek to exist in a steady state, where the parts of the system are in a balance.
- The parts of the system are continuously interacting.
- Systems have boundaries, which are more defined in some cases than in others.
- A system can be affected by stresses that occur within or without the whole system.
- Stress leads to change in the system, causing alterations in the balance that can either be temporary or permanent.
- Systems can be open or closed. In closed systems the boundary is easily crossed or affected by external stimuli.

2.4 KINGS CONCEPTUAL FRAMEWORK

According to King's conceptual framework:

- Human beings are open systems in constant interaction with the environment.
- That nursing focus is people interacting with the environment.
- The nursing goal is to help individuals and groups to maintain health.

King (1981:145) points that King's conceptual framework is based on the common understanding that concepts of perception, interaction, transaction, self, role growth development, stressors, coping and time, health and nursing are essential components of the discipline of nursing.

King (1995:14-22) goes on to say King's conceptual framework is composed of three dynamic interacting open systems:

- personal systems, consisting of individuals
- interpersonal systems, made up of dyads, triads, small and large groups
- social systems, composed of the family, school, industry, social organizations and health care delivery

2.5. INTERACTING SYSTEMS

2.5.1 The personal systems

In systems theory individuals are viewed as systems. According to Fawcett (1989:104), individuals' perception of self, body image, time, and space influences the way they responds to their environment and objects and events in life. As individuals grow and develop, their perception of themselves changes. Perception influences individuals' behaviour. King (1997:15) states that perception is a characteristic of human interaction while persons communicate with each other. For example, the nurse and the patient interact to establish the patient's view of the current and future situation.

Pearson and Vaughan (1990:126) state that people are

- reactive beings, who react to situations and things, as they perceive them
- oriented in time and space, thus their perceptions are related to the present past and future

- social beings, who interact with and adapt to their environment.

2.5.2 The interpersonal systems

In the home-based care family care givers, patients, and professional health care providers interact with and support each other. All the parties concerned are expected to contribute to the decisions related to the care provided (Meleis 1997:34).

Froman (1995:225) refers to the interaction between patients, family care givers and professional health care providers to determine goals and the means to achieve them as transactions. Part of the interaction (transaction) is the exchange of information in order to ensure an acceptable level of care, verify the accuracy of the information, and assess the situation. Thereafter solutions to the problems can be worked out.

Stress affects how individuals interact and react. While caring for chronically/terminally ill patients at home, the family members are constantly required to adjust to various constraints. The family will either respond negatively or positively. Negative factors, such as inadequate income, cause stress and have a negative impact on care giving. The family's ability to effectively respond to stimuli is an indicator of positive functioning. Examining the family provides community health nurses with clues to existing and potential health problems. Anxiety over a lack of adequate resources in HBC can inhibit individuals' ability to cope with the situation. Chronic care giving can serve as a personal or interpersonal stressor (Carson 2000:609). Too many stressors, such as lack of access to and unavailability of resources for HBC, may lead to an inability to function.

In any society people have defined roles. Professional health care providers, patients and family care givers have specific roles in the HBC situation. In some situations, children provided HBC for their chronically/terminally ill parents.

Role conflict occurs when life situations make the family do things not normally expected of them. In this study there were many female headed households but they did not have jobs to provide for their families. This prohibited the family care giver from providing quality care. Peoples' growth and development are influenced by genetic traits and the environment. In the context of HBC, the individuals' experiences and development influence how they cope with problems.

2.5 .3 The social systems

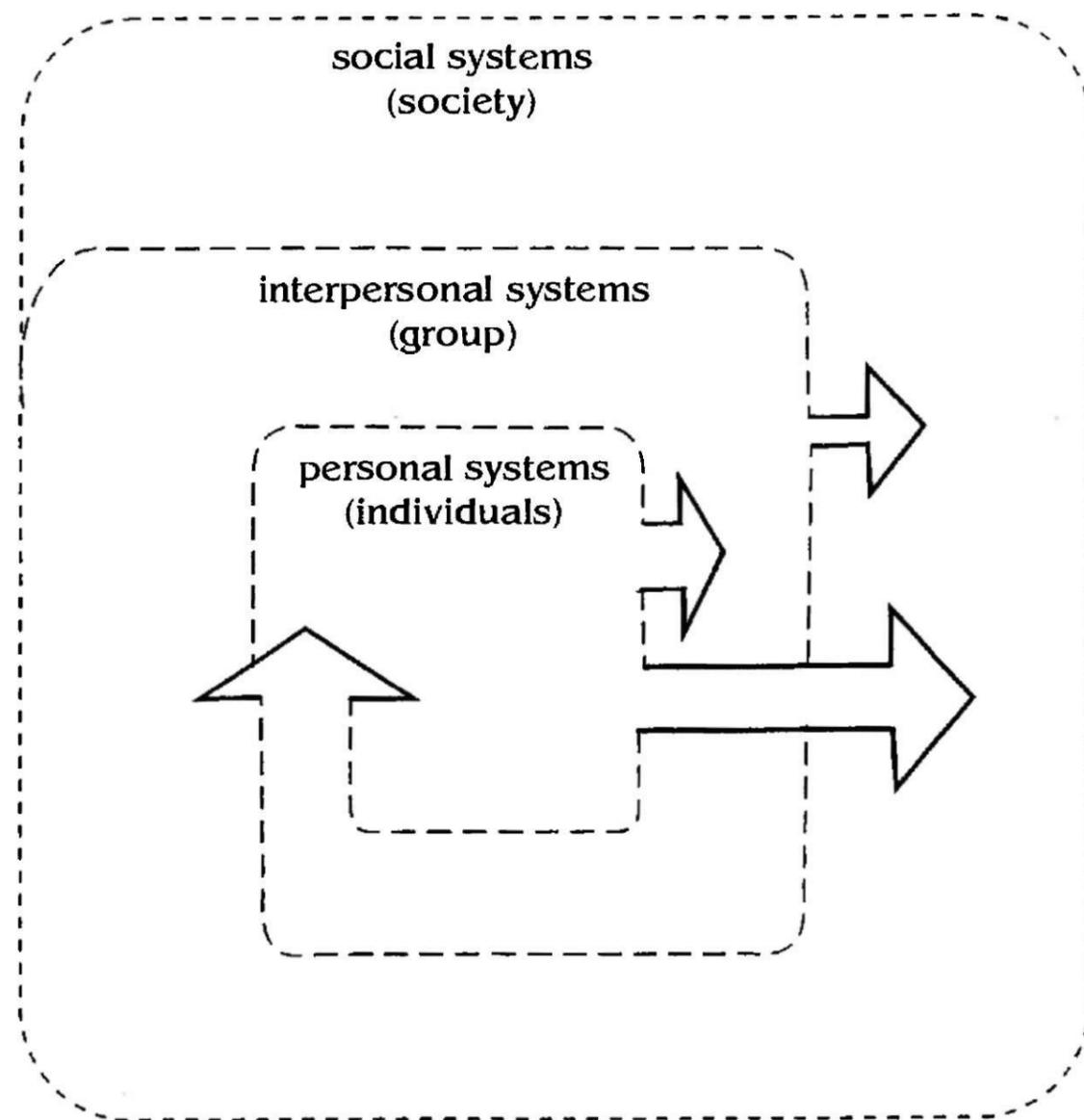
Cookfair (1996:20) says that the community as a whole is a social system. Community members form links with each other. Changes in the larger system may cause repercussions in the subsystems. When health programmes are eliminated or reduced, services to health care providers are limited, access to care is reduced and families may be denied the care needed.

Whyte (1994:188) defines a social system as an organised boundary system of social roles, behaviours and practices developed to maintain values and mechanisms to regulate practices and rules.

Figure 2.1 below illustrates three dynamic interacting open systems which are personal systems (individuals), interpersonal systems (groups) and social systems

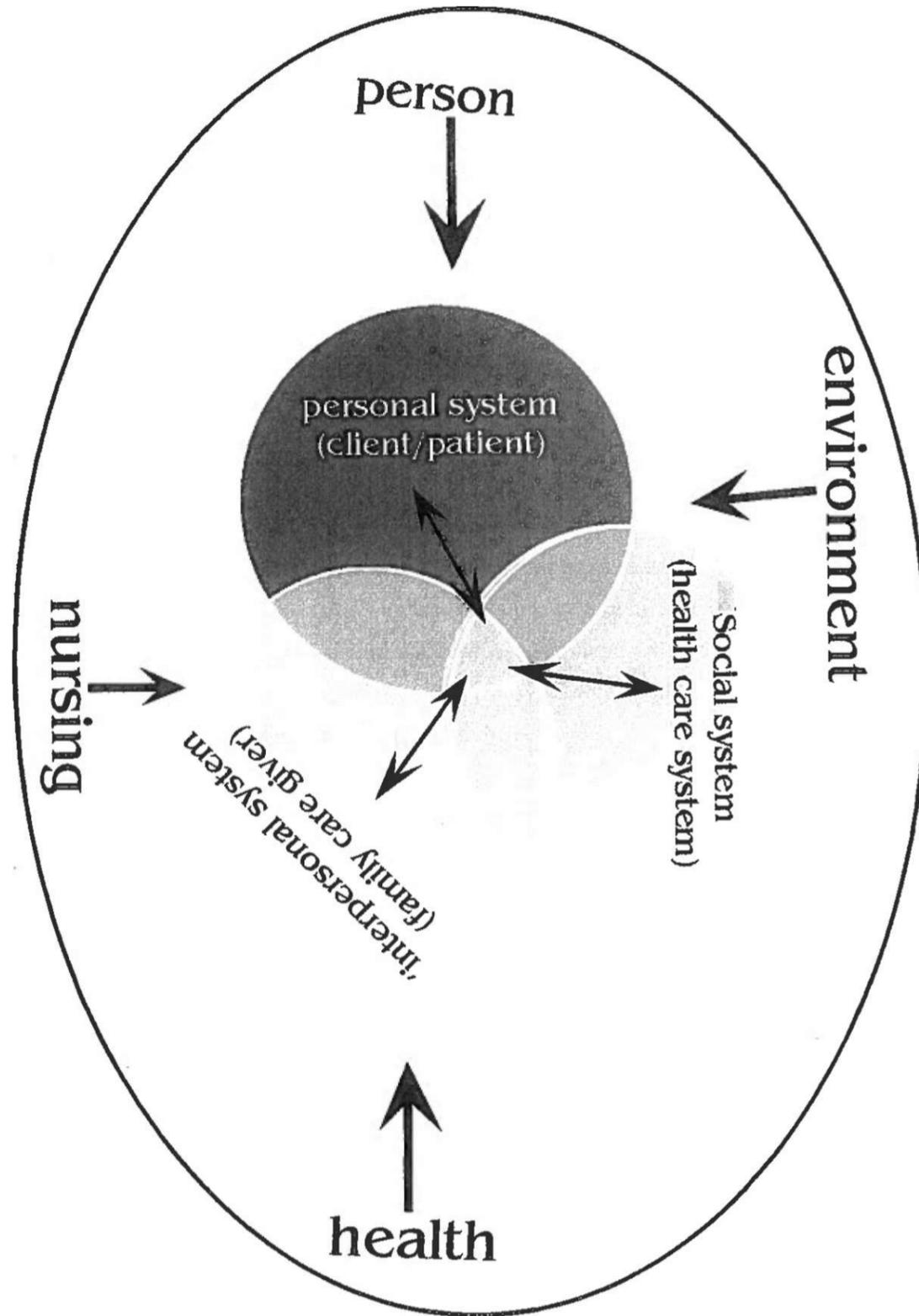
(society). The three systems represent the environment that influence growth, development work and health of individuals, groups and societies.

FIGURE 2.1 KING'S INTERACTING SYSTEMS FRAMEWORK



Source: FROM KING (1971:20)

FIGURE 2.2 KING'S CONCEPTUAL FRAMEWORK



Source: adapted from whyte 1994:190

Figure 2.2 represents dynamic interacting systems. The three systems are individuals, groups and communities that interact with their environment to achieve goals. The chronically/terminally ill patients, professional health care providers and family care givers interact constantly in a changing environment. Mutually agreed decisions are vital to any system in order to achieve goals. Two way arrows indicate communication that takes into consideration each participant's views. The health care system is part of the social system. In this study, health care systems were considered open, and professional health care providers as subsystems that interacted with the family care givers and the chronically/terminally ill.

Figure 2.3 below illustrates the various systems and subsystems in the home based care situation. Each system or subsystem impacts is a starting point for interaction. The two way arrows indicate how one system affects the other. The family as an organizational structure is composed of members that make up communities and societies. For interaction to be effective all parties must be actively involved in decisions that concern their health.

FIGURE 2.5 FAMILY HEALTH CARE SYSTEMS

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Source: adapted from Stanhope and Lancaster 1996:454

In home-based care the individual is viewed within a health care system to achieve optimal health. Family functioning is affected by what happens in the environment. The individual functioning of the chronically/terminally ill is affected by what happens in the family. The professional health care provider (nurse) functions as a subsystem in the health care system.

2.6 SYSTEMS THEORY AND THE NURSING PROCESS

According to Leddy and Pepper (1998:170), using the systems theory to guide the nursing process directs the assessment of the nurse-patient interaction or relationship. The steps in the nursing process are discussed below.

2.6.1 Assessment

Meleis (1997:341) states that King's theory is useful for assessing individuals and group relationships in nursing. It can then be concluded that the systems framework is an appropriate tool for assessing the community. Leddy and Pepper (1998:220) emphasise that assessment "incorporates perceptions, communication and interaction of the nurse and client".

The systems approach enabled the researcher to take a holistic view of the clients, families and communities and their environment. This made it possible to assess how the families functioned and how the interaction between family members affected each other. Pearson and Vaughan (1990:129) point out that the nursing process is an "interactive process of action- interactive - reaction - transition".

2.6.2 Nursing diagnosis

Nursing diagnosis reflects client concerns and disturbances in health. It also indicates the nurse's understanding and analysis of the patient's social systems, perceptions, interpersonal relations as well as coping with feelings of dependency. Leddy and Pepper (1998:16) state that interacting models emphasise social acts and relationships between people.

2.6.3 Planning

In this stage of the nursing process, the nurse and the client set goals and agree on the means to achieve them. In the home-based care situation, the professional health care provider (nurse), the family care giver and the chronically/terminally ill patient plan together.

2.6.4 Implementation

After planning procedures and setting the goals for the care of the chronically/terminally ill, the parties concerned start implementing the programme in order to achieve the goals they set.

2.6.5 Evaluation

This stage evaluates how effectively the home-based care programmes are implemented. The effectiveness of the programme is also assessed and/or whether they need to be changed.

According to Meleis (1997:341), King's theory is also useful for long-term nurse- patient relationships and evaluating satisfaction, goal achievement and effective nursing care. As individuals interact with their environment, their

perceptions influence their behaviour and their health. Evaluation determines whether goals are achievable and achieved.

2.7 SYSTEMS APPROACH TO FAMILY NURSING

Whyte (1994:187) holds that a systems approach to family nursing offers support for a nursing relationship with families caring for chronically/terminally ill children. She emphasises the need for a holistic view of the family and the relationship of its parts. The nurse herself is a subsystem in a health care system. A narrower view restricts the information collected and insight into the problems. Consequently, important interrelated aspects of the problem or resources that can be utilized to promote health and alleviate distress can be missed in the assessment. An individual family care giver lives in a family.

Family members are viewed as interacting elements in a family system. Leddy and Pepper (1998:35) point out that the "family systems focus on the interactions between members and the family system and on other systems. A change in one member of the family system will affect the entire system." It is important to note that this approach focuses on the interactions of various parts of the system rather than descriptions of the functions of the parts themselves.

In systems theory, units at all levels of analysis contain interacting components that function in a coordinated way to deal with the environment. The practice in Botswana over the years has been for the younger members to care for older members of the family. This pattern has changed as a result of the AIDS pandemic where large numbers of young people are dying.

Lewis and Lubkin (1998:84-85) view individuals, families, and communities as systems with interacting and interdependent subsystems. Since chronic illness involves adjustment among family members' abilities to perform their roles, new roles need to be established in the family system. Care giving is complex and makes heavy demands on the care giver.

2.8 SYSTEMS THEORY APPLIED

A systems approach assists the community health nurse to understand the interaction in a family and the norms and expectations of the family. This approach provides insight into family interaction, expectations and adaptation to members' needs and the community.

A systems approach explains complex client-environment interaction and facilitates the assessment and analysis of clients and their relationships in a dynamic environment (Whyte 1994:187). No theory as yet covers all the aspects of the chronically/terminally ill.

The researcher examined the individual, the family, together with the structures and functions of these systems and their relationships thereby to explore how the family responded to their environment. The response of the chronically/terminally ill to their illness depends greatly on the environment. This is important as the needs of the patient affect the family structure. The systems approach promotes insight into the interaction in a family and their environment. For example, a diagnosis of chronic/terminal illness such as cancer in any family affects all family members and the family functioning as a unit (Cooley 1995: 210; Clark 1999:823).

Nursing interventions need to be geared to the family as a unit as well as the individuals members. It is important that the nursing interventions focus on the greatest challenges or problems faced by the clients and the community at large.

This study focused on care giving by family care givers and how the patients and family care givers interacted with professional health care providers during the care giving process. Clark (1996:64) states that each family meets unique problems in caring for the chronically ill. The way the family responds to those problems depends entirely on their level of development. According to Lubkin and Larsen (1998:32), the "degree of difficulty the family goes through in adapting to the crisis depends on the strengths, limitations and unresolved personal issues each family member brings into the situation." In any family where there is chronic/terminal illness there will be role changes.

2.9 CONCLUSION

Chapter 2 discussed the systems theory as the conceptual framework for this study. The researcher adopted a systems approach to the study in order to assess the quality of home-based care of the chronically/terminally ill in Botswana.

Chapter 3 covers the literature review conducted by the researcher.

CHAPTER 3

LITERATURE REVIEW

3.1 INTRODUCTION

Chapter 2 discussed the conceptual framework of this study. This chapter discusses the literature reviewed on home-based care for the chronically/terminally ill undertaken by the researcher. According to Marshall and Rossman (1995:28,41), the literature review "refines and redefines the research questions ... provides a framework of the research and identifies the area of knowledge that the study intends to expand" and furthermore "validates the importance of the study focus ... develops explanations during data collection and analysis".

For the purpose of this study, the literature review was focused on a systems approach and the perceptions and experiences of clients/patients, family care givers and professional health care providers in home care and their interaction. The researcher paid particular attention to research on home-based community health care, health care systems, the needs of the chronically/terminally ill, family care givers' needs, support systems, and quality, assurance injjipnie-based health care.

3.2. HOME-BASED HEALTH CARE IN THE COMMUNITY

3.2.1 The community as a system

The community operates as a system. According to Klainberg, Holzemer, Leonard and Arnold (1998:125), the "community can be viewed as individuals, families, and aggregates within a community. There is a reciprocal relationship among these component parts and the community as a whole. Interventions that support the health of individuals, families, groups and populations within the

community support the community's health. The community is reflected in the health of its subsystems of components parts ... Individuals, families, and communities are linked and influence each other ... This interrelationship is an illustration of wholeness..."

Nurses working in the community need to identify the strengths, weaknesses and problems of the individuals, the families and the community itself. The community is a system and the interrelationships among the various subsystems and suprasystems must be considered carefully. The family is a social system to meet the members' needs through their relationships with one another. The health of a community reflects the health of a family.

McKinnon (1997:115) states that the nurse's "relationships with systems in the community are equally important as those with the client systems. For effective implementation of change within family systems, it is important for a community health nurse to understand interaction with external systems influencing clients and their families".

3.2.2 The person and the family as a system

A person is an open system made up of parts that add up to a whole.

Dysfunction of one part disrupts the whole system. Systems have internal and external environments (Frey 1995:226). The individual is influenced by changes in the environment.

Subgranon and Lund (2000:170) describe individuals, families, and communities as systems that have interacting and interdependent subsystems. Chronic illness involves adjustment among family members and in their ability to perform their

roles and necessitates the establishment of new roles in the family system. Subgranon and Lund point out that in Thailand most care givers perceive care giving as a family's responsibility and are reluctant to trust outsiders with the care of their relative. Outsiders are only allowed to assist with any other type of support except personal care. In a study of Japanese family care givers, Yamamoto and Wallhagen (1998:695) found that their culture prevented family care givers from using formal health care services unless they found it impossible to render care.

Biegel, Sales and Schultz (1991:29) point out that although a family has several members, only one carries the burden of caring. The other family members take a passive or "bystander" role in caring for the terminally/chronically ill relative.

The personal attributes of the chronically/terminally ill can also influence family care givers. For example, people who are physically attractive and/or have a pleasant personality find more people willing to care for them. People find it easier to care for patients who have similar attitudes, religious and political beliefs, and belong to the same nationality and race. Sometimes people adopt the care giving role to avoid indebtedness and for rewards and approval. The care giving role can also be assumed for social reasons, such as reciprocity, equity, or social responsibility (Biegel et al 1991:29).

3.3 THE IMPACT OF CHRONIC/TERMINAL ILLNESS ON THE PATIENT AND FAMILY

Chronic/Terminal Illness has a great impact on both the patient and the family. Wagner (1996:470) found that caring for a chronically/terminally ill asthmatic child caused some parents to doubt their ability to care for the child and became overprotective. The added expense of caring for their chronically ill child placed a

financial burden on the family.

In a study of Finnish families with children with chronic conditions such as diabetes, rheumatic arthritis, and asthma, Hentinen and Kyngas (1998:317) examined problems of care and treatment of the children. Most of the families had other children besides the chronically ill ones. In the study the average Finnish family had four children. Hentinen and Kyngas found that families had problems providing care and treatment. Families with strong emotional support adapted well to the child's chronic illness. Parents who received adequate support from professional health care providers reported less conflict and better acceptance of the diagnosis. Furthermore, Hentinen and Kyngas reported that mothers found it more difficult than fathers to care for their chronically/terminally ill children and therefore needed more formal support.

Dildy (1996) examined the nature and impact of suffering in chronically/terminally ill people with rheumatoid arthritis. Dildy (1996:180) found that experience of suffering had a significant effect on the respondents' lives and resulted in a constant struggle, loss of dreams, restructuring a future, and sometimes social withdrawal. The degree of interaction between patient and nurses varied. Some patients found nurses sympathetic, sensitive, receptive, caring, cheerful and gentle. Loss of independence and personal control seriously affected the overall health of the individual.

Miller (1998:4) points out that at the time of the diagnosis, the news can be devastating for the patient and family. According to Meadows, Marechal and Catalan (1999:47), reaction to diagnosis can be shock, horror, numbness and incomprehension. The extent to which patients cope depends on factors such as pre-morbid personality and psychosocial situation.

Wainright (1997:45-48) examined the experiences of patients with chronic liver disease and found that the development of this chronic illness was often insidious up to the time of diagnosis. The patients and relatives were uncertain of the condition until the diagnosis. The patients reported periods of doubt, and negative feelings about their physical limitations and used this as a criterion for the decline in health. Nevertheless, the patients wanted to retain their independence as far as possible and live a normal life as illness progressed.

In a study in Iceland on the direct and indirect effects of chronic physical conditions on depression, Vilhjalmsson (1998:610) found that chronic physical conditions are associated with higher domestic and economic strain, lower social support, self esteem and mastery, and higher depression.

Chronic cardiovascular patients were often found to have other medical problems, were depressed, felt they were overprotected, and had a negative perception of their care givers. Care givers also viewed them negatively (O'Reilly & Thomas 1998:302).

3.4. PROBLEMS OF CARE GIVING

Home-based care shifts the burden of caring for chronically/terminally ill patients to the family. Assuming greater responsibility is physically and psychologically taxing on the members. Craft and Willadsen (1992:580) state that care that benefits the patient sometimes places a significant burden on the family care givers.

Gaynor (1990:120) found that women with longer care-giving experience had more health problems than ones with less experience. Young women care givers

experienced more psychological stress than older ones. Professional health care providers should assist and guide care givers whose health is likely to decline as a result of care giving. The community health nurse plays a central role in the care process, especially in home-based care.

O'Neill and Rodway (1998:59) found that insight on the part of the health workers into the family perceptions of care giving and relationships between patients and the family improves the quality of care, lessens the chances of readmission to hospital and lowers costs.

Significant others who care for HIV/AIDS patients need skills in home-based care. In 1998, the Ministry of Finance and development Planning assessed the situation of orphans in Botswana and found that there was an urgent need for counseling.

Ingstad, Bruun and Tlou (1997:357) found that in Botswana, the elderly bear the greatest burden of caring for orphans whose parents (the middle generation) died of AIDS. The World Health Organization (2000b: 22) confirms that in Botswana most family care givers are elderly and have little or no knowledge of HIV/AIDS. Often family care givers die soon after the HIV/AIDS patient. Government and private sector initiatives are aimed primarily at patients and not family care givers. According to Shaibu (1997:129) the health problems of the elderly in Botswana are rooted in their socio-economic and political status. Shaibu found that the health care system does not make adequate provision for the needs of the elderly and family care givers struggle with meager resources to care for the elderly at home.

3.5 PATIENT EXPECTATIONS OF NURSES *

A study of HIV positive and AIDS patients, Mullins (1996:12) found that patients wanted to be treated as individuals and, nurses to be accepting, respectful,

accessible and knowledgeable. Patients were hesitant to express what they desired in nursing care because they feared possible sanction by nurses or other health care providers.

3.6 ROLE OF THE FAMILY IN HOME-BASED CARE "

As indicated in chapter 2 the family is an open system consisting of subsystems (Cooley 1995:208). Kellet (1997:58) states that family members who deliver care to older relatives usually do not adopt an action- oriented approach to care giving, but instead view caring in terms of concerns, commitments and objectives to achieve. Klainberg, Holzemer, Leonard and Arnold (1998:238) emphasise that

family is a living social system and the community health nurse renders care to individual family members in the context of the family.

In home based care, the family has to cope with emotional burdens, share tasks, and provide material supplies, skills, and guidance to improve the patient's ability to handle situations.

Hellzen, Asplund, Sandman and Norberg (1999:660) found that the major role of families of mentally disturbed people was to provide material and emotional support to patients. Some families consistently asked for more information and participation in the patients' treatment. However, it was extremely difficult for family care givers to be loving when the patients were severely mentally disturbed.

In a study of family care givers of people with AIDS in USA, Powell-Cope (1994:324) found that the primary motive for interaction between the family care giver and the professional health care provider was to negotiate and ensure the best care for the person with AIDS.

McKinnon (1997:114) points out that in order to involve the family in care giving, community health nurses should focus on the positive aspects of the family and

- identify the family's strengths to encourage the family's optimal functioning
- identify the family's internal resources to demonstrate confidence in the family's ability to influence the situation.
- Encourage the family to access available and appropriate external resources to promote independence
- understand the family dynamics to enhance effective interaction.

The interaction between the patient, the family care giver and the professional health care provider is meaningful when all the parties participate in decisions.

Elliot and Luker (1997:244) examined the experiences of mothers of children with atopic eczema in northwest England and found that the mothers regarded caring for their chronically ill children as extra mothering. The mothers felt taxed as they were always exhausted, and also had no time for their own activities and also had to cope with severe physical demands. These findings could be applied to Botswana where most families are headed by women. Fifty- two percent of these households are in rural areas and mothers or daughters bear the burden of care giving.

Family caregivers have unique relationships, needs and resources. Health professionals need to recognise them as people with skills and experience in giving care. Learning from family care givers contributes to the quality of care provided by all.

3.7 FAMILY CARE GIVER NEEDS '

Caring for the chronically/terminally ill patients at home places a grave responsibility and has a great impact on family care givers. Family care givers have been found to suffer from depression, stress, physical, mental and emotional exhaustion and personal health problems, among other things (Banks 1998; Clipp & George 1990, Coyne 1997; Gaynor 1990; Hileman & Lackey 1990; Kutz, Kutz & Given 1995; Laidlaw 1996; Lubkin & White 1998; Meadows, Marechal & Catalang 1999; Reid 1998; Ministry of Health 2000b; Sato, Ricks & Watkins 1996, and Wong 1995)

Laidlaw (1996:444) found that family care givers of people with obsessive compulsive disorders require support and may be considered consumers of mental health services themselves. She states further that there is a need for research into primary and long- term health care services. Clipp and George (1990), Coyne (1997), Heamen (1995), and others also stress the need for support for family care givers and help for them to cope.

Families of cancer patients mostly have emotional, social and financial problems and at times, physical symptoms (Hileman & Lackey 1990:772). Buehler and Lee (1992:1307) found that the more a cancer patient's condition deteriorated, the greater the burden on rural family care givers, particularly in respect of financial and other resources.

Family care givers respond differently to chronic illness, especially in the terminal phase. Some are more resourceful than others at finding alternative strategies to cope with stress. In the terminal phase, family care givers mainly need information and support. Their chief concern is that the patient be kept

comfortable. Their most difficult aspect of home care for family care givers is watching a loved one deteriorate. After the death of the terminally ill patient their biggest problem is coping with their bereavement.

Hunt and Zurek (1997:3230) state that patient education benefits patients and families because it helps them to feel confident about being discharged and their follow-up care as they have some knowledge about their condition and their questions have been answered.

In Botswana, the Ministry of Health (1998c: 25) evaluated the community home-based care project in Molepolole and Tutume sub-districts and found that the majority of chronically/terminally ill patients and family care givers had little, if any, knowledge about nutrition, infection control and administering or taking medications. In addition, the quality of educational materials for patients, care givers and the community was unsatisfactory. There was also a need to improve the training for professional health care providers, patients and family care givers.

3.8 THE HEALTH CARE SYSTEM

King's conceptual framework for nursing views the community as a whole as a social system Evans (1991:7). The health care system is part of the social system. Health care systems are open systems, which interact with patients and family care givers.

Health care systems differ from country to country (Huttlinger 2000:67-68).

There are generally five categories of health care systems:

(1) Free enterprise system. In this system services are delivered in an open market with little government intervention or control over supply (eg, the USA).

- (2) Welfare system. This type of system provides equal services for all members of the population and social security finances the system. The government plays a major role in providing health care services (eg, the U K, France, Canada, Sweden, Norway, and Germany).
- (3) Transitional system. In this system, the government and the private health sector, are responsible for health services (eg, India).
- (4) Under developed systems. This type of system, is found in underdeveloped countries and is poorly organized, of health care delivery especially in rural areas (eg, Malawi)
- (5) Socialist system. In this type of system health care is controlled by the government and the health facilities are state owned (eg, China).

In developing countries traditional healing and Western medicine and health care are used. In Tanzania, for example mental health services incorporate traditional healing and Western practices (Kilozo and Simmons 1998:420). The government of Botswana recognises traditional healers and treatment in health care.

3.9 BOTSWANA'S HEALTH CARE SYSTEM

Botswana's health care system is based on the principles of primary health care in the Alma Ata Declaration, (WHO 1978:3). The basic objectives include access to essential health care services by all citizens, whatever their financial status, and the equitable distribution of health resources and services.

The Ministry of Health is responsible for the health care system and services in the country and local government services are responsible for the implementation of primary health care. Botswana has nine districts, which are divided into twenty-three health districts responsible for primary health care delivery in hospitals, clinics, health posts and mobile health stops.

At district level, the district health team works the clinics, health posts and health centers. At clinics and health posts, the district health team receives community home-based care referrals, liaises with community organizations and coordinates follow-up visits and care. In regard to home-based care, the district health team fulfils an advisory, supportive, administrative, supervisory, patient care and monitoring role and evaluates the home care programme.

The health care system in Botswana is built on a referral hierarchy of services consisting of a network of 2 referral hospitals, 15 district hospitals, 14 primary hospitals 182 clinics, 309 health posts, and 834 mobile stops.

Figure 3.1 below illustrates the organization of Botswana's national health care system.

FIGURE:3:1 ORGANISATION OF THE NATIONAL HEALTH CARE SYSTEMS IN BOTSWANA

Type of facility	Health and medical personnel	
Two: referral hospitals One psychiatric hospital One private hospital	Specialised professional such as medical specialist, nurses midwives pharmacists, and allied health officers	
16 District Hospitals	District medical officers, nurses and allied health professionals, midwifery	
14 primary hospitals	Physicians , nurse, midwives and allied health officers	
204 clinics two types of clinics: *clinics with maternity beds *clinics without maternity beds	Nurses midwives and family welfare educator(FWE)	
314 Health posts	nurses mtdwives and family welfare educator(FWE)	
687 mobile stops	Managed by health teams nurses and midwives.	

Source: Ministry Of Health 1996:1

3.9.1 Health care service delivery

Compared to some developing countries, Botswana's infrastructure and public services are "of a good standard" (Ministry of Health 1997:60). With regard to health services, the furthest that people have to travel to a health care facility is 15km. A serious problem, however, is the shortage of doctors and nurses.

- **Medical doctors**

Botswana has a chronic shortage of medical doctors. According to the Ministry of Health (1999a: 19) the doctor patient ratio was 2,5:10000, which indicates the size of the problem. As patients far outnumber doctors, most patients are only seen by nurses. Nurses are allowed to prescribe drugs because of the shortage. The home care treatment plans for patients have to be certified by a doctor. The training of doctors is a government priority. According to the Ministry of Health (1999b: 10), there is a need for professional health care providers, especially doctors, to undergo training in tuberculosis management as most were unaware of the Botswana National Tuberculosis (TB) Programme.

- **Nurses**

Nurses constitute the biggest body of professional health care providers in Botswana, with 4265 trained nurses in the country. This indicates a nurse -patient ratio of 26.5:10000 which, in turn, indicates a shortage of nurses as well (Ministry of Finance and development Planning 1997-2003: 19).

Nurses are allowed to make initial diagnosis of patients. In serious cases, such as TB, the medical doctor will then review the patient. This and the fact that doctors have to certify home care treatment plans make the effective implementation of home-based care difficult (and slow it down).

3.9.2 Home-based care

Home-Based Care has become a world wide trend and practice (Powell-Cope, 1994; Riccio, 2000; Twigg, 1994; Wong, 1995; Xu & Hu, 1996; Buehler & Lee, 1992). The ever growing number of chronically/terminally ill patients in Botswana necessitates home-based care (see chapter 1, section 1.1.13).

In Botswana, mainly registered nurses are involved in home-based care. Many are tutors in district hospitals, clinics or health posts. Their duties include home visits, ordering and delivering supplies, and providing health education to patients, families, the community, and family care givers.

The government has employed sixteen social workers in Botswana. Their recommended functions include needs assessment, home visits, training, counseling and resource allocation or distribution. Given the size of the country and the population, and poverty rate, there is a serious shortage of social workers. The researcher found, for example, that social workers did not do home visits in Molepolole, where this study was conducted.

3.9.3 Quality care

Providing quality care to chronically/terminally ill patients is a challenge. The key to quality is collaboration between health care providers to provide maximum care and avoid duplication. McCollin (2001:420) states that an "interdisciplinary approach is essential in home-based care nursing. This calls for collaboration, which can only be achieved through the efforts of all health care professionals. When an interdisciplinary approach is missing in home care, the services that are given by individual health care providers becomes fragmented".

Cherin, Simmons & Hillary (1998:40) support a team or multidisciplinary approach. They developed the transprofessional model of care for terminal AIDS

patients to receive both palliative and curative care. Unlike the traditional model, where only one nurse took care of a patient, the transprofessional model provides co-ordinated care by a team of health providers. Cherin, Simmons and Hillary found that the transprofessional approach provided continuity of care and services because they were co-ordinated and the patients' quality of life was improved. Patients' concerns were taken into consideration in decisions on care.

Chronically/terminally ill patients and their family care givers need to be assisted by professional health care providers to negotiate the health care system to obtain needed services. This can otherwise be a very frustrating and stressful experience for both patient and family (Marek and Rantz, 2000:2).

Ellis and Whittington (1993), Kock (1994), and others stress quality in patient care. An important aspect of quality health care is effective follow-up. Weaver, Perloff and Waters (1999:28) state that families and patients expect follow-up after discharge. Community health nurses are faced with the challenge of establishing effective follow-up systems. For this reason, it is the duty and responsibility of the community health nurse to assess the family and the patient's needs before discharge from hospital.

Medical clinics have been set up throughout Botswana to follow up on chronically/terminally ill patients in Botswana. However, with the shortage of doctors and nurses, there are still gaps in the follow-up of chronically/terminally patients.

3.10 THE ROLE OF THE COMMUNITY HEALTH NURSE

In home-based care the community health nurse fulfils many roles and is required to provide a wide range of services. For example, as a teacher, she has to educate patients, family care givers and the community about health, hygiene, diet and health care among other things (Hunt & Zurek, 1997; Clark, 1999). Referrals are an important part of her role and duties because an effective referral system is a vital link between the various services and resources (Smith & Maurer 1999). As a direct care giver, the community health nurse applies "the principles of epidemiology and the nursing process to the care of clients at all levels- individuals, groups and communities" (Clark 1999:57). Dreyer (1997:29) states that the " management role of the community health nurse is that of supervisor of family health care, running clinics, planning health care programmes and referring clients to other professionals". The community health nurse is also an important change agent (or agent of change). Clark (1999; 64) describes a change agent as " one who initiates and brings change". In order to be a change agent, the nurse needs to take into account the personal and environmental factors that impinge on the health of families and communities.

These are some of the roles and functions of the community health nurse.

3.11 CONCLUSION

This chapter covered the literature review conducted by the researcher. The focus of the literature review was on a systems approach to nursing, the perceptions and experiences of chronically/terminally ill patients, family care givers and professional health care providers of home-based care, and their interaction. The researcher was particularly interested in research on home-based care, the needs of chronically/terminally ill patients, family care givers' needs, approaches to home based nursing care, and the role of the community health nurse.

Chapter 4 discusses the research methodology of the study.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 INTRODUCTION

This chapter describes the research methodology of the study namely, the research design and data-collection methods.

4.2 RESEARCH DESIGN

The researcher employed a descriptive triangulated design which combined qualitative and quantitative methods to explore the patients', family care givers' and professional health care providers' perceptions and experience of the home-based care provided. Qualitative and quantitative data complement each other and provide a fuller picture than could be obtained from a single method (Polit and Hungler 1994:250). For this reason, this study combined qualitative and quantitative methods.

4.3 DELIMITATION OF STUDY

Botswana is divided into twenty-three health districts. Kweneng is one of the major health districts and is made up of Kweneng East and Kweneng West. Molepolole is one of the major villages in Kweneng East.

The current study was conducted in the Molepolole East between 1996 and 2001. The researcher chose this area for the study because the number of chronically/terminally ill people in Kweneng East indicated a serious need for home-based care. Furthermore, the researcher had worked in the community for ten years as a lecturer in community health nursing and was familiar with the health care system.

4.4 SAMPLE POPULATION

Polit and Hungler (1997:224-226) describe sampling as "the process used to select a portion of the population to represent the entire population" and go on to say that "a convenient sample entails the use of mostly available people as study participants". In this study, a convenient sample, composed of 25 chronically/terminally ill patients, 25 family care givers, and 25 professional health care providers, was used to gather information. The researcher interviewed the family care givers and patients in their homes. The professional health care providers were interviewed at the health care facilities, namely the Bokaa, Boribamo, Borakalalo, Kgosing and Council clinics.

4.4.1 Patients

All the patients in the sample were diagnosed with a chronic/terminal illness, were nursed at home (i.e., were in home-based care) were residents in Molepolole East around the clinics mentioned above. The patients had to be listed on the clinic register and ones who received active personal assistance and direct supervision with at least the following daily activities: bathing, dressing, feeding, assistance to go to the toilet or mobilization.

4.4.2 The family care givers

The family caregivers included spouses, children, relatives, friends, neighbours or any significant others who gave direct care to a chronically/terminally ill family member for at least eight hours in a day, and had stayed with the patient for a period of not less than a week. The family care givers did not have to be blood relatives. Only one family care giver and patient per household were interviewed as this allowed for the biggest representation of clients/patients and family care givers in Molepolole East.

4.4.3 Professional health care providers

The professional health providers include nurses, social workers and/or doctors who had been in contact and had cared for the patients any time from admission to discharge and their stay at home.

4.5 PERMISSION TO CONDUCT THE STUDY

The researcher sought permission to conduct the study from the Office of the President, the Ministry of Health, the Office of the District Commissioner, the tribal authorities and local health authorities. The Office of the President is the official body that grants permission to conduct studies for all studies through universities outside Botswana.

4.6 DATA COLLECTION METHODS - =

The researcher visited the community, the District Commissioner, the district health team and the clinic and hospital staff before conducting the study. The researcher explained the nature and purpose of the study and assured all the respondents that the information would be treated with the utmost confidentiality. The respondents were also assured of anonymity; that is, that their names would not be disclosed. This would encourage the respondents to disclose information freely.

The researcher selected the questionnaire as the main data-collection method or tool because it is the most convenient means of obtaining a great deal of information from a number of respondents at a time.

Some of the family care givers and patients were illiterate or semi-literate therefore the researcher administered the questionnaire by means of structured

interviews with those individual respondents. The researcher recorded the respondents' answers to the questions in writing because most of the respondents were not comfortable with the idea of tape-recording the sessions. The respondents that were literate were given the questionnaires to complete.

In the case of the professional health care providers, the researcher distributed the questionnaires to the health facilities for completion and arranged to collect the completed questionnaires at a later date.

4.6.1 Questionnaires

The researcher compiled three questionnaires for the three categories of respondents (chronically/terminally ill patients, family care givers and professional health care providers). Most of the questions were the same for all the respondents. While some were aimed at one specific category and their situation, perceptions and experience. A covering letter accompanied the questionnaires to introduce the researcher, explain the topic and purpose of the study and the purpose of the questionnaire, assure the respondents of confidentiality and anonymity, thank them for their participation and contribution, and tell them that they would be informed of the findings as well as the outcome of the study should they so wish.

4.6.2 Interviews

As mentioned earlier, some of the chronically/terminally ill patients and family care givers were illiterate or semi-literate which made it necessary for the researcher to conduct interviews with them. The researcher therefore structured the interviews on the questionnaire for those patients and family care givers.

4.7 PILOT STUDY

Before a study can be conducted the instrument to collect information has to be pre- tested. Clifford and Gough (1990:44-45) describe a pre - test or pilot study as "a trial run to determine in so far as possible whether the instrument is clearly worded or free from major biases and whether it solicits the type of information envisaged".

For Dempsey and Dempsey (1992:75- 78), a pre test is "the process of testing the effectiveness of the instrument in gathering the appropriate data by administering the instrument to subjects, and then evaluating the instrument's strength and weaknesses and revising it as necessary". They point out that research instruments "must possess basic attributes, which assure us that they provide dependable measurements of the variables under investigation". The most important attributes are validity, reliability and usability. Dempsey and Dempsey (1992:75) state further that the content validity "of a measuring instrument is the extent to which the instrument's representative behaviour is then identified. A number of experts in the field of the study topic are then asked to examine each item and to make judgement regarding how well the items and entire instrument reflect the previously defined content area. Face validity is determined by inspecting the items to see if the instrument contains items that measure the variables in the content area. Face validity is based entirely on the subjective judgement of investigator... construct validity is the degree to which a measuring instrument measures a specific strait or construct".

Dempsey and Dempsey (1992:76) state that the usability of a measuring instrument refers to the practical aspects of using it. It is important to consider the usability of an instrument".

Polit and Hungler (1997: 295) point out that the "reliability of a quantitative measure is a major criterion for assessing its quality. Lo Biondo-Wood and Haber (1994:248) state that reliability refers to the degree of consistency and accuracy with which an instrument measures an attribute. There are three important aspects of reliability, namely stability, internal consistency, and equivalence.

The researcher conducted a pilot study on three professional health care providers, three family care givers and three chronically/terminally ill patients who were not members of the sample population for the study. The objective of the pilot study was to test the validity and reliability of the questionnaires. After the pilot study and discussion, adjustments were made to the questionnaires where necessary.

The questionnaires for the patients and family care givers were translated into Setswana, the lingua franca of Botswana. The reason for this was that some residents in Molepolole do not speak or understand English. Therefore the researcher had to conduct interviews with them (structured-based on the questionnaire). The patients and family care givers that were literate completed the questionnaires for themselves.

4.8 Three specific questionnaires > —»

Three specific questionnaires to evaluate the home-based care of the chronically/terminally ill were developed for this study (see annexures 4, 5 and 6 respectively). For the purpose of discussion the questionnaires will be referred to

- **Patient questionnaire**
- **Family care giver questionnaire**

- **Professional health care provider questionnaire**

A covering letter introduced the researcher to the respondent, outlined the purpose of the study and the questionnaire and assured the respondents of confidentiality. Instructions on how to complete the questionnaire were given and the respondents thanked for their input.

4.8.1 Research questions — — —

The following were the research questions for this study and the respondents that answered them.

- **Question 1 Are the needs of chronically/terminally ill patients being met by the family care givers and the professional health care providers?**

The researcher wanted to establish whether the health care delivery system addressed the needs of patients. This was important, as the services rendered should be relevant and appropriate to the clients' needs. Only the patients answered this question. *

- **Question 2 Are the needs of family care givers being met?**

In this question information was collected on what the family care giver's role constituted. This question was addressed only to family care givers.

- **Question 3 Is there a relationship between the professional health care providers attitudes towards chronically/terminally ill persons and their occupation?**

Information on the attitudes of professional health care providers is vital to understand why they deliver services that their patients and family care givers do not appreciate. This question was directed only to professional health care providers.

- **Question 4 What type of support do the professional health care providers give to the family care givers of chronically/terminally ill patients.**

The question wanted to establish whether the respondents had assistance from others beside themselves. The researcher needed to know how much the respondents were aware of the services available to them. Only the family care givers responded to this question.

- **Question 5 Is there a difference between the professional health care providers, patients, and the family care givers' level of satisfaction with the home- based care service provided?**

This question sought to establish whether the level of satisfaction among the three categories of respondents was the same. This was a measure of the efficiency and effectiveness of the health care system in its delivery of services. All the respondents were required to answer this question.

- **Question 6 What are the patients, family care givers and professional health care providers' perceptions of the home based care given, and the acquisition and utilisation of resources?**

The researcher wished to know the experiences and perceptions of all the respondents of the utilization of the resources made available to them by the health care system.

4. 8.2 The questionnaires

Questionnaires were developed to assess clients/patients, family care givers, and health care providers. Areas covered were biographic details, perceptions and experience of their problems, use of and level of satisfaction with home based care and the general health status of patient, family caregivers and professional health care providers. Other areas covered by questions were needs of family care givers, patients and health care providers, attitudes of health care providers, support given to family care givers, home care in relation to acquisition of resources. Questionnaires combined open-ended and closed questions relating to care of the chronically/terminally ill in the home.

The use of both questionnaires and qualitative interviews was to increase understanding of the experience of those with chronic/terminal illness and their care givers. Semi- structured interviews were seen as the most appropriate method of data collection to allow a degree of consistency of approach whilst also allowing for explorations of particular issues of importance to respondents.

There was need in Botswana to develop tools that are specific to measure care giving in chronic/terminal illness. The researcher hopes that the three tools developed in this study were sensitive, objective and appropriate to elicit the data required for care of persons with chronic illness in the home.

4. 8. 3 fatkiit-questionnaire (interview guide) , __

The objective of this questionnaire was to collect data on the patients' perceptions and experience of HBC in Molepolole East (see annexure 4).

Biographic data

Items 1-11 the questionnaire had questions that asked about the patients' age, sex, ward, education, marital status, income and accommodation.

Content of questionnaire

Items 12-17, used qualitative and qualitative components in the questionnaire with open-ended and closed questions in the instrument. Thus the researcher will have quantitative information that will be expanded by the qualitative information available. Open-ended questions in the questionnaire were used to allow the respondents to express beliefs, values and feelings. This type of a question provided the researcher with information about aspects to which responses from different participants could not be predicted.

Items 18-19

A Likert scale was used to determine the needs of patients. The respondents were asked to respond to the questions by indicating the extent to which they agreed with the statement as follows:

Strongly Disagree (SD), Disagree (DA), Neutral (N), Agree (A), Strongly Agree (SA).

Item 20

This set of questions used a five point Likert scale to measure the level of satisfaction with family care givers. The respondents were asked to indicate their feelings by ranking as follows:

Very Dissatisfied (VD), Dissatisfied (D), Unsure (U), Satisfied (S), and Very Satisfied (VS)

4.8. 4 Family care giver questionnaire

The objective of this questionnaire was to collect data on the family care givers' perceptions and experience of HBC in Molepolole (see annexure 5).

Biographic Data

Items 1-11,16-17.

This part of the questionnaire asked about the family care givers' age, education, marital status, income, accommodation, relationship, and duration of care giving. This information was necessary to understand the characteristic of the respondents.

Items 12 -15,17

These items had closed questions. These types of questions tend not to examine a particular response in detail as the respondents are forced to answer in a given way. In order to add depth to the responses the researcher allowed the respondents to add personal comments to most of the closed questions.

Item 16,22, 25, 26, 32

Rating scales were used to measure attributes. Subjects were asked to rate themselves. They had to choose from three or more responses or from the agree or disagree scale.

Item 18-21,23-24,27-28,

The questions were both open-ended and closed. The open-ended questions allowed respondents to freely express their views and opinions.

Items 30-31

A Likert scale was used to measure degrees of agreement or disagreement. The respondents had to tick the item that most approximated their attitude or opinion.

4.8.5 Professional health care provider questionnaire

The objective of this questionnaire was to gather information on professional health care provider perceptions and experiences with HBC in Molepolole (see annexure 6).

Items 1-3

Collected biographical data, such as the health facility, catchment areas and occupation.

Items 4-6, 8,10-12,16

Rating scales were used to measure attributes and the subjects were asked to rate themselves. They had to choose from three or more responses or from the agree or disagree scale. The researcher included a number of alternatives from which the respondents had to choose what best described their personal interpretation of the question. In this way validity was added to the questionnaire. Items that required knowledge were stated factually to minimize guessing. The respondents were allowed to add remarks and expand on the issues.

Items 9,17,18

A Likert scale was used to measure the level of satisfaction with home care providers. The respondents were asked to indicate their feeling by ranking options from among the following:

Very Dissatisfied (VD), Dissatisfied (D), Unsure (U), Satisfied (S), Very Satisfied (VS). A space was also provided for the respondents to express their feelings, beliefs and opinions.

Quantitative analysis

The descriptive and inferential were employed using the Statistical Package for the Social Sciences (SPSS) programme. According to Polit and Hungler (1999:439) the rationale for using descriptive statistics techniques is to reduce data into manageable proportions summarising and describing various data characteristics. Descriptive

techniques used included frequencies, percentages, distribution and variation diagrams. These data incorporated measures of central tendency and measures of variability. Measures of central tendency described the average member of a sample while the measure of variability described how much dispersion there was in the sample (Lobiondo-Wood and Haber **1990:377**).

4.9 Conclusions

This chapter discussed the research methodology including the overall plan of answering the research questions. The data collection method, the sample, and the setting of the study were described. A detailed description was given of the three data collection tools for the patient, family care giver, professional health care provider. Chapter 5 analyses the data and presents the findings.

CHAPTER 5

DATA ANALYSIS AND INTERPRETATION

5.1 INTRODUCTION

This chapter analyses and interprets the data collected on the patients, family care givers and professional health care providers' perceptions and experiences of home-based care. How these groups interacted had a direct bearing on the quality of health care provided at home. The purpose was to determine the effectiveness and efficiency of HBC services at Molepolole.

5.2 DATA ANALYSIS

The researcher used questionnaires and interviews as data-collection techniques.

The Statistical Package for Social Scientists (SPSS) was used for data entry and analysis. The respondents were asked the following questions:

1. Are the needs of the chronically/terminally ill patients being met by the family care givers and the professional health care providers?
2. Are the needs of the family care givers being met?
3. Is there a relationship between the professional health care providers attitudes towards the chronically/terminally ill persons and their occupational ranks?
4. What support do the professional health care providers give to the family care givers of chronically/terminally ill patients?
5. Is there a difference between the chronically/terminally ill patients', family care givers' and professional health care providers' levels of satisfaction with the home- based care provided?
6. What are the patients', family caregivers' and professional health care providers' perceptions of the actual care given, acquisition and utilization of resources?

25 patients, 25 family care givers and 25 professional health care providers were selected.

5.2.1 Presentation of quantitative data

5.2.2 Biographic details of patients

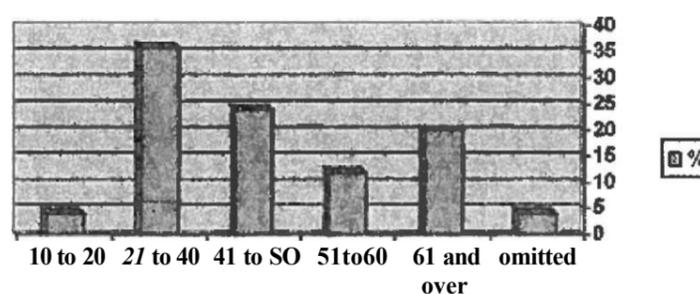
The sample consisted of 25 chronically/terminally ill patients.

The patients' gender, age, marital status, level of education, unemployment status and monthly income were examined. The analysed data is depicted in the following graphs and tables:

Gender

Of the 25 respondents 14(56%) were male 2(8%) were female, 9(36 %) did not indicate their gender.

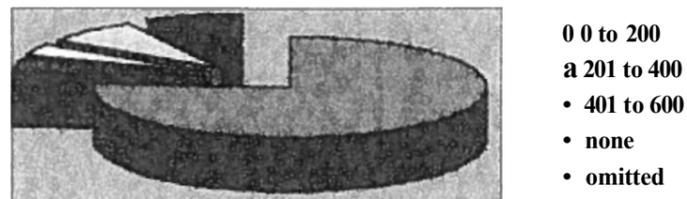
Figure 5.1 Age of patients N=25



Of the 25 respondents, 1 (4%) was aged between 10 and 20, 9(36%) were between 21 and 40, 6(24%) were between 41 and 50, 3(12%) were between 51 and 60, 5(20%) were 61 and over, and 1(4%) did not indicate their age.

It seems youths are the most vulnerable to chronic illness such as HIV/AIDS leaving the burden of care-giving to the elderly in the families who are likely to be suffering from chronic illness themselves.

Figure 5.2 Monthly Income of chronically/terminally ill patients N-25



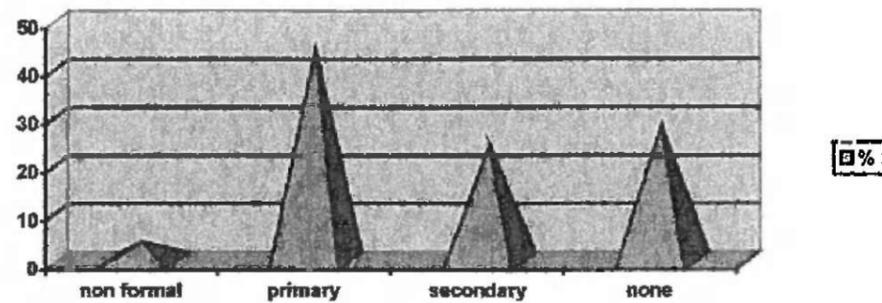
The income status of the 25 patients indicated that 19(76%) had an income of between P 0-200, 1(4%) had an income between P201 and 401, 1(4%) had an income of P401 and 600, 2(8%) did not indicate their income. Lack of finances predisposes one to poverty which increases the lack of resources among the families rendering HBC.

P = Pula currency of Botswana

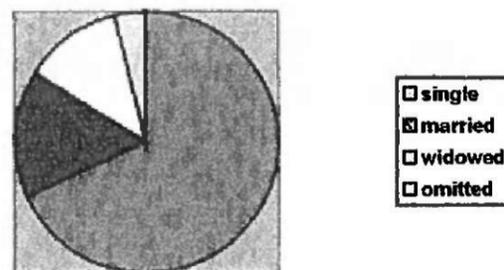
Figure 5.3 Employment status of patients N-25



Of the 25 respondents 1(40%) was self employed, 2(8%) were domestic workers, 19(76%) not employed, 3(12%) did not indicate their employment status (see annexure 8a). A large number of unemployed suggests poverty in a community. The households are unable to buy the necessary resources for HBC.

Figure 5.4 Patients' level of education N= 25

Of the 25 respondents 11 (44%) had primary education, 6 (24%) had secondary education, 1(4%) had non-formal education and 7 (28%) had never been to school. The patients who had never been to school were 28% indicating a large group of patients that were illiterate. Lack of education predisposes patients to poor health as they depend on nurses to share information with them. In this study a few patients had done primary education.

Figures 5.5 Patients' marital status N=25

Of the 25 respondents 17 (68%) was single, 4 (16%) were widowed, 3 (12%) were married and 1 (4%) did not indicate their status. The results indicate many patients that are single. Members of the family became care givers for these patients.

Figure 5.6 Patients' monthly income N=25

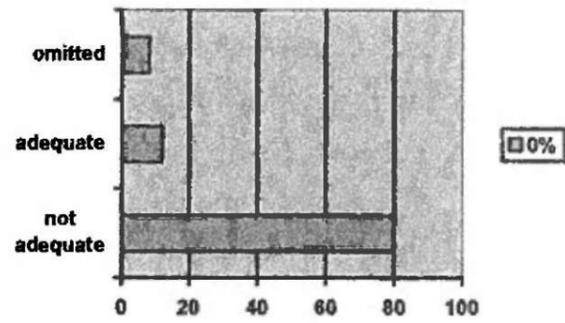
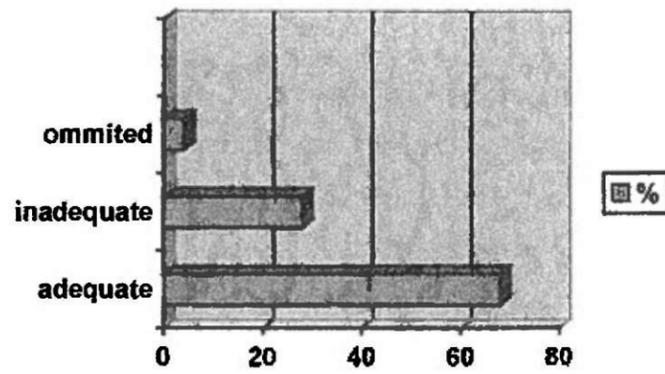


Figure 5.6 shows that of the 25 respondents, 20 (80%) indicated that their income was not adequate, 3(12%) felt their income was adequate and 2(8%) did not indicate their status. Results in this study indicate many patients that are very poor and are likely to depend on welfare rations for a living.

Figure 5.7 Patients' accommodation N=25



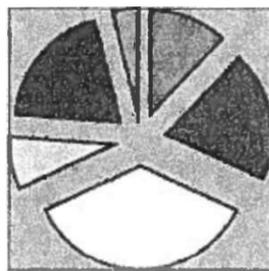
Of the 25 respondents, 17 (68%) said their accommodation was adequate, while 7(28%) indicated that their accommodation was inadequate and 1 (4 %) did not

indicate their status. The number of rooms per household ranged from 1 to eleven rooms. The number of the people living in one household ranged from 3 to 20. The people living in one room ranged from 1 to 12. Patients that needed to be cared for per household ranged from 1 to 3. The results indicate there is overcrowding in some households which is likely to predispose household members to poor hygiene standards of living. Adequate accommodation is vital for effective care giving by family care givers

5.2.3 Biographic data on family care givers

This sample consisted of 25 family care givers who were interviewed. All the family care givers (25) were female.

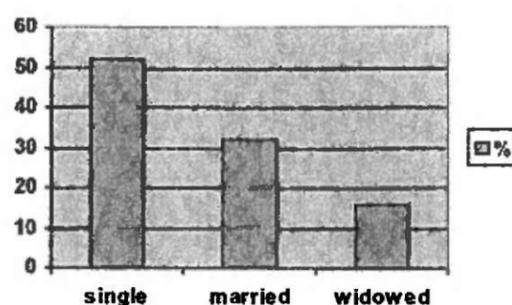
Figure 5.8 Age of family care givers N-25



- 10 to 20
- 21 to 40
- 41 to 50
- 51 to 60
- 61 and over
- omitted

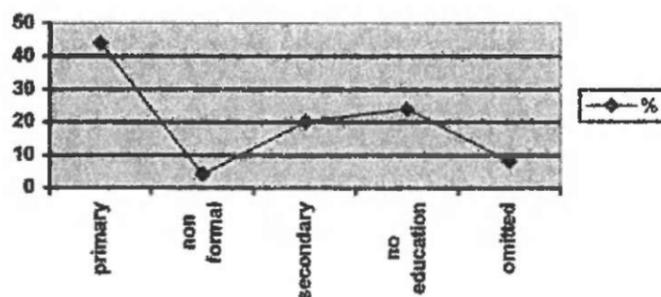
The ages of the family care givers ranged from 10-60 years. Of the family care givers, 3(12%) were aged between 10 and 20 years, 5 (20%) were aged between 21 and 40 years, 9 (36%) were aged between 41 and 50 years, 2(8%) were aged between 51 and 60 years, 5 (20%) were aged 61 years and over and 1(4%) did not indicate their age. In this study the care giving burden of the chronically/terminally ill patients rested with the elderly who were mainly female.

Figure 5.9 Marital status of family care givers N=25



Of the 25 respondents 13 (52%) were single, 8 (32%) were married, 4(16%) were widowed (see annexure 8b). The greater numbers of family care givers were single females who are likely to have other roles in the household besides caring for the chronically/terminally ill.

Figure 5.10 Educational level of family care givers N=25



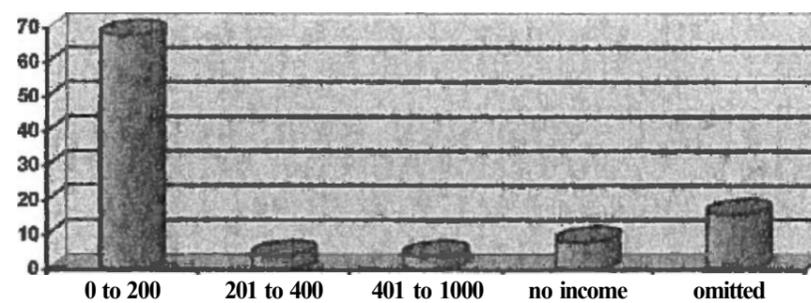
Of the 25 respondents, 11(44%) had primary school education, 6(24%) had no education, 5(20%) had secondary education, 1 (4%) had non-formal education and 2(8%) did not indicate their level of education. Less than half of the family care givers had primary education This indicates a group of people that have very little education and probably not conversant with many health issues.

Figure 5.11 Employment status of family care givers N=25



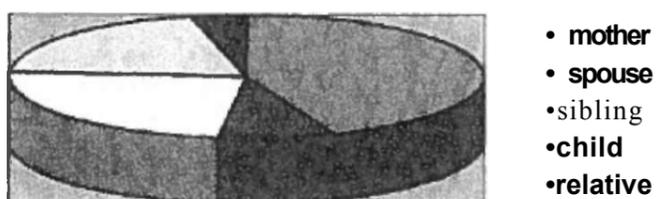
Of the 25 respondents, 22 (88%) were not employed, 1 (4%) were government employees, 1(4%) worked for an NGO and 1(4%) worked for famine relief. The large number of the unemployed among family care givers predisposes them to poor health as families and makes care giving a complex issue.

Figure 5.12 Monthly Income of family care givers N=25



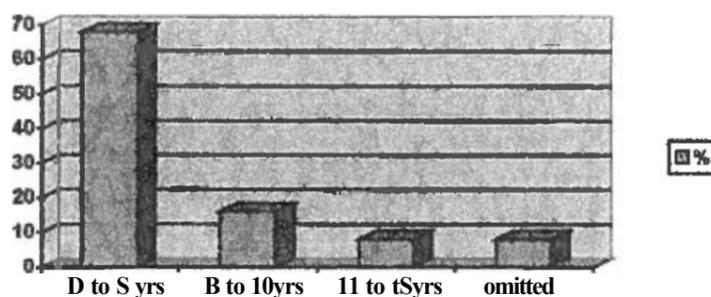
Of the 25 respondents 17 (68%) had an income of between P0 and 200, 2 (8%) had no income, 1 (4%) had an income between P201- 400, 1 (4%) had an income of P801- 1000 and 4(16%) did not indicate their income. The income is very low that makes it necessary for family care givers to subsist on social welfare rations where they are available.

Figure 5.13 Relationship of family care givers to patient N=25



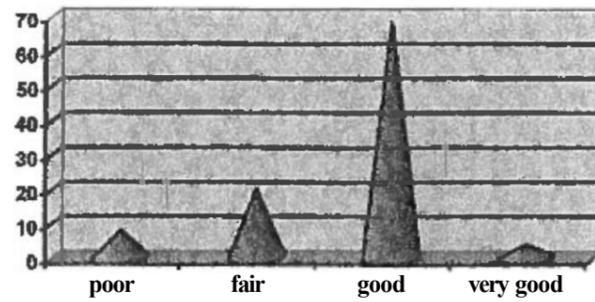
Of the 25 respondents 11(44%) were patients' mothers, 6(24%) were their siblings, 5 (20%) were their children, 2(8%) were spouses and 1(4%) were relatives. It seems the female parents carry the burden of care giving in families yet they are the most that are unemployed and have other roles to play in the community.

Figure 5.14 Duration of care giving to patient N-25



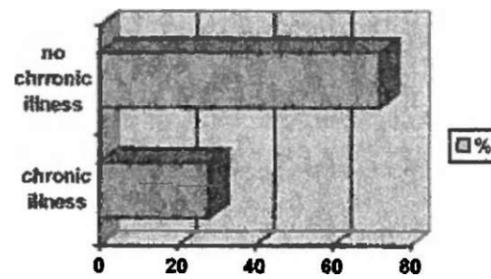
Of the respondents, 17(68%) had cared for the patients for 1 to 5 years, 4 (16%) had cared for them for 6 to 10 years, and 2 (8%) had cared for them for 11 to 15 years. It seems more than fifty percent of the family care givers had cared for a patient for a period of one to two years. This is likely to cause strain and stress among family care givers.

Figure 5.15 Health of family caregiver N=25



Of the 25 respondents, 17(68%) indicated that their health was good, 5(20%) indicated that their health was fair, 1(4%) indicated that as very good health, 2(8%) indicated they were in their poor health. The study results indicate that the family caregivers had good health which was an advantage for care giving.

Figure 5.16 chronic illness of family care givers N=25

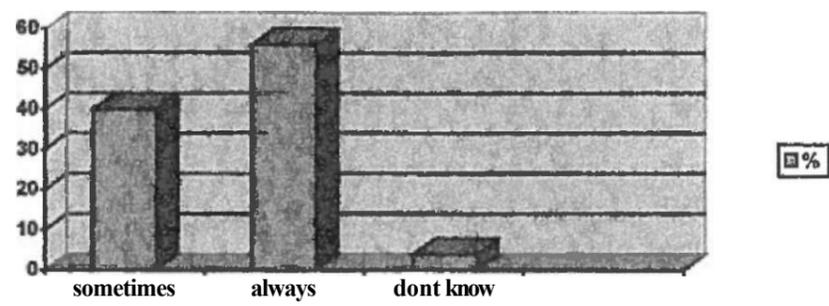


Of the 25 respondents, 7 (28%) indicated they had chronic illness and 18 (72%) indicated they had no chronic illness. It seems the family care givers with chronic illness felt their health was good, as it did not interfere with their daily functioning.

5.2.4 Professional health care provider

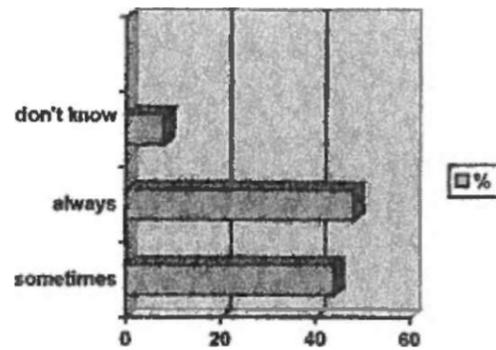
This sample consisted of 25 professional health care providers who were interviewed.

Figure 5.17 Patients' utilization of available resources N=25



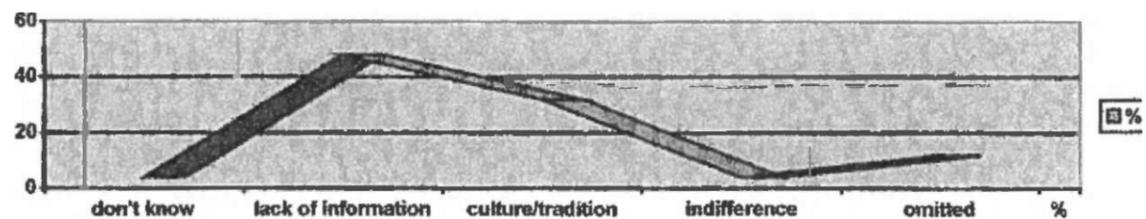
Of the 25 professional health care providers, 10(40%) said patients sometimes utilized resources on HBC, 14 (56%) indicated patients always used the available resources, 1(4%) did not know the extent patients used the resources. It seems only 56% of the professional health care providers said patients utilize available resources. This means the other half does not use the available resources. The care provided is likely to be inadequate as these people are on low income.

Figure 5.18 Family care givers' utilization of available resources N=25



Of the 25 respondents, 11(44%) indicated that family care givers sometimes utilized available resources, 2(8%) did not know the extent family care givers utilized available resources, 12(48%) said family care givers always utilized available resources. It seems about fifty percent of the family care givers used available resources. The rest did not use them.

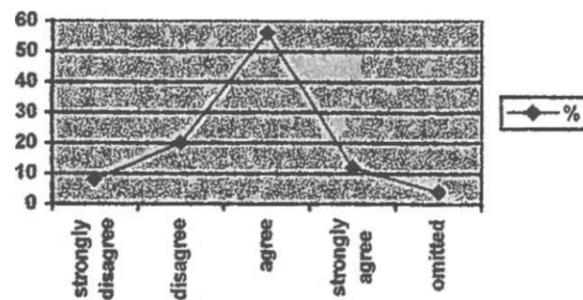
Figure 5.19 Contribution to under utilization of resources N=25



Of the 25 professional health care providers, 1(4%) did not know what contributes to under utilization of HBC resources, 12(48%) indicated that patients under utilization was attributed to lack of information, 8(32%) said culture/tradition was attributed to under utilization of HBC resources, 1(4%) attributed under utilization to indifference, 3(12%) did not respond. The results of the study indicated that 48%

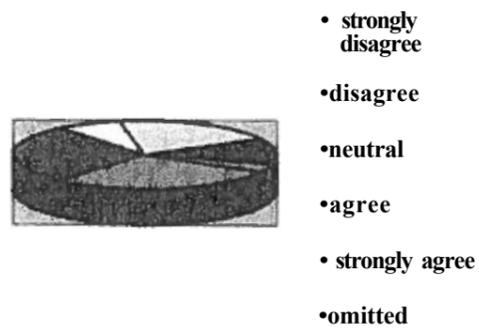
of the professional health care providers attributed under utilization of HBC resources to lack of information.

Figure 5.20 Patients admission when family care giver is no longer able to manage
N=25



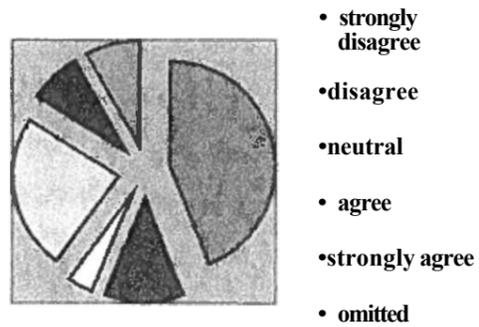
Of the 25 professional health care providers, 2(8%) strongly disagreed that patients be admitted when family care giver no longer can manage, 5(20%) disagreed that patients be admitted when family care giver no longer can manage, 14(56%) agreed that patients be admitted when family care giver no longer can manage, 3(12%)strongly agreed that patients be admitted when family care giver no longer can manage, 1(4%) did not indicate when patients should be admitted. The majority of the nurses did agree that patients be readmitted when the care giver was no longer able to manage. The health care system should take care of those individuals who have no care giver at home.

Figure 5.21 Patients' admission when supplies are inadequate at home N=25



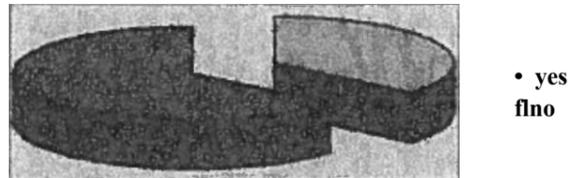
Of the 25 professional health care providers, 7(28%) strongly disagreed that patients be re- admitted when supplies are inadequate at home, 7(28%) disagreed that patients be re- admitted when supplies are inadequate at home 3(12%) strongly agreed that patients be re- admitted when supplies are inadequate at home, 5(20%) agreed that patients be re- admitted when supplies are inadequate at home, 2(8%) were neutral, 1(8%) did not indicate when patients should be re-admitted. It seems professional health care providers want patients cared for at home even when they have no resources to look after themselves.

Figure 5.22 Patients' admission when family care giver does not want the responsibility any longer N=25



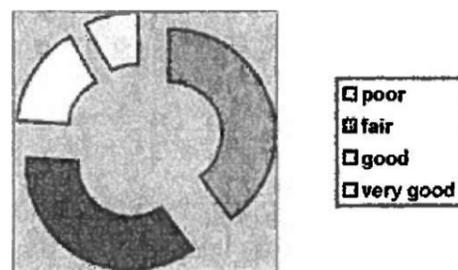
Of the 25 professional health care providers, 11(44%) strongly disagreed that patients be admitted when family care giver no longer wants responsibility, 3(12%) disagreed that patients be admitted when family care giver no longer wants responsibility, 1(4%) were neutral, 2(8%) strongly agreed that patients be admitted when family care giver no longer wants responsibility, 6(24%) agreed that patients be admitted when family care giver no longer wants responsibility, 2(8%) did not indicate when patients should be admitted. Family care givers should be given the liberty to give care at home or decide not to do it. In this study professional health providers do not want family care givers to have a choice.

Figure 5.23 Accessibility of needed health services to all family care givers
N=25



Of the 25 professional health care providers, 9(36%) indicated that health service were accessible to all family care givers, 16(64%) said health services were not available to all family care givers. Results of this study indicated that health services were not accessible to family care givers. This has implications on the care provided to patients

Figure 5.24 Time for home visits. N=25



Of the 25 professional health care providers, 2(8%) said time given for home visits was very good, 4(16%) said time was good, 10(40%) indicated time was poor, 9(36%) said time given was fair. Failure to follow up patients after discharge means there is no opportunity to evaluate the progress made by the patients and no feedback is received.

Question 1: Are the needs of chronically/terminally ill patients being met by family caregivers and professional health care providers?

This question was answered by patients (see chapter 4, section 8.1)

Table 5.1 Patients' needs met by the professional health care providers and family care givers

Patients' needs	Professional health care giver		Family care giver	
	Mean	Std Deviation	Mean	Std Deviation
1. Confort, sleep, and cleanliness	2.28	0.94	3.83	1.05
2. Administration of medications	3.04	1.14	3.64	0.76
3. Spiritual support provided	2.68	0.75	3.3	0.88
4. Predictable orderly environment	2.71	1.12	3.52	1.05
5. Feeling of security and safety	2.6	1.04	3.5	1.06
6. Love and affection from significant others	2.88	1.09	3.72	1.02
7. Acceptance by family members	3.08	1.08	3.63	1.1
8. Communicating relationship with significant others	3.04	1.06	3.5	1.18
9. Feeling of self-reliance	2.7	1.02	3.24	1.24
10. Feeling of usefulness	2.17	1.04	3	1.22
11. Feeling of independence	2.64	0.91	3.08	1.04
12. Unity with loved ones	2.88	1.05	3.44	0.92
13. Appreciation from others	2.77	1.06	3.04	1.02
M. Dignity preserved	2.92	1.04	3.04	1.02
15. Involvement in decisions about own health	2.64	1.04	2.84	1.03
16. Acceptance of condition	2.88	1.01	2.96	1.27
17. Knowing about own illness and treatment	2.44	0.96	2.68	1.14
18. Feeling of self worth	2.3	0.76	2.52	1.16
19. Fear of dying	2.36	0.99	2.68	0.95
20. Assistance with care or help with equipment	2.36	0.86	2.78	0.85
21. Counselling about personal hygiene	2.36	0.95	2.48	1.05
22. Finance and family ability to provide care	2.12	0.78	2.56	1.12
23. Quality of health teaching	2.6	0.96	2.44	0.96
24. Quality of supervision in home based care		0.87	2.46	0.98

From table 5.1 the average ranking over the scale 1 to 5 for professional health care providers on all the items included in the list of patients needs ranges from a low of 2.12 for the item of "Finance and family ability to provide care" to a high of 3.08 for "acceptance by family members". The lower end of the scale corresponds to strongly agree.

On the other hand the ranking of the family care giver is lowest for "Quality of health teaching" at 2.48, and highest for comfort, sleep and cleanliness at 3.83. The measure of variability (standard deviation) for these two rankings shows moderate variability which indicates similar perceptions of the patients' needs for both the professional health care providers and family care givers

The study results also indicate that of the patients, 11(44%) felt that their needs were not met by the family care givers or the professional health care providers. The following was found: Comfort, sleep and cleanliness, feeling of security and safety, love and affection from significant others: 15 (60%) of the patients felt family care givers met their needs. However, of the patients, 4 (16%) felt that the professional health care providers met their needs. On feeling of security and safety: 5 (20%) of the patients felt that the professional health care providers met their needs. On love and affection from significant others: 8 (32%) of the patients felt professional health care providers met their needs (see annexure 8a).

»—On "communicating relationship with significant others: 10 (40%) of the patients felt that their needs were met by the professional health care providers. On acceptance by family members: 11 (44%) of the patients felt that their needs were met by the professional health care providers. In addition 13 (52%) of the patients felt that their needs for acceptance by family members were met and of communicating relationship with significant others (see annexure 8a).

- Of the patients, 8 (32%) felt that the professional health care providers made them feel useful, 5 (20%) were made to feel independent, 10 (40%) felt that their need for self-reliance, usefulness, and independence was met by the family care givers (see annexure 8a).
- Of the patients, 10 (40%) felt that the professional health care providers preserved their dignity, 6 (24%) felt professional health care providers accepted their condition; 9 (36%) felt family care givers preserved their dignity and acceptance of their condition (see annexure 8a).
- Of the patients, 8 (32%) felt family care givers met their needs for involvement in decisions about own health and informed them of their own illness. The professional health care providers did not involve patients in decisions about their own health and letting them know about their own illness. 2(8%) patients were involved in decisions about their health, 4 (16%) patients knew about their illness from the professional health care providers (see annexure 8a).
- With regard to feeling of self-worth, of the patients, 2 (8%) felt that the professional health care providers met their needs and 5 (20%) felt health care providers helped them with their fear of dying. Of the patients, 7 (28%) felt that the family caregivers met the need for feeling of self worth and 6 (24%) felt that they helped them with their fear of dying (see annexure 8a).
- The need for assistance with care or help with equipment: Of the patients 5 (20%) had their need met by the family care givers, and 3 (12%) felt that the professional health care providers met their needs (see annexure 8a).

- Of the patients, 7 (28%) felt that the need for finance and the family ability to provide care were met by the family care givers, 6 (24%) felt that the professional health care providers met this need (see annexure 8a)

In order for communication to be effective there must be a general agreement on the goals and means to achieve those goals and objectives refer 2.5.2. Interactions between the family and professional health care providers are either positive or negative.

Question 2: Are the needs of family care givers met? ^

The respondents to this question were 25 family care givers (see chapter 4, section 8.1).

Of the 25 respondents, 1(4%) indicated that transport was accessible, 21 (84%) indicated that transport was not accessible and 3 (12%) did not indicate.

Of the respondents, 3 (12%) indicated they had no access to finance, 19 (76%) and 3 (12%) did not indicate.

Of the respondents, 6 (24%) indicated they had no access to medical supplies, 15(60%) did not have access to medical supplies and 4(16%) did not indicate

Of the family care givers, 19(76%) adopted the care giving role without any preparation. Of the family care givers, the health status of 22(88%) was not assessed before they adopted the care giving role.

Of the family care givers, 9 (36%) had not mastered the care giving skill and cared for a relative because they had no choice (see annexure 8b).

Of the family care givers, 15 (60%) needed clothing, blankets, special education, home visiting from the professional health care providers, transport to health facilities, housing, and referral to appropriate agencies (see annexure 8b).

Of the family care givers, 15 (60%) did not feel confident to give care. Of the family care givers 21(84%) had problems with transport and 13 (52%) rated the supervision of home care as poor (see annexure 8b).

Of the family caregivers, 7 (28%) were chronically ill themselves (see annexure 8b).

Of the family care givers, 20 (80%) indicated that they needed the following HBC services: family support, peer support, religious support, voluntary organisation, treatment centres, financial help and medical supplies (e.g. gloves bandages...) (see annexure 8b)

Of the family care givers
otswana citizens to have access to good quality services within reasonable travelling distances by 2016.

Home-based care has multiple administrative structures at local as well as national level, which permit professional health care providers to put together appropriate care and services for the patients, but at the same time create inefficiencies and administrative costs. The services become inequitably distributed, creating a situation where some get adequate supplies while others are left out.

This study found that the needs of the family care givers were not met by the professional health care providers.

5.2.5 Chi-square test of independence

The researcher wished to investigate any association between occupation and the professional health care providers' attitudes towards the chronically/terminally ill patients. This was done by means of a chi-square test of independence and the test statistic was given by:

$$\chi^2 = \sum \frac{(O - E)^2}{E}$$

Where O was the observed frequency in a cell and E was the expected frequency in that cell. The E was calculated by multiplying the row and column totals corresponding to a cell and dividing by the grand total. The null hypothesis stipulates independence between the two factors, that is no association. The rule is reject the null hypothesis if the p-value is less than the level of significance ($\alpha = 0.05$), and accept the null hypothesis if the p-value exceeds the level of significance.

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• **Question 3 is there a relationship between the professional health care providers' attitudes towards the chronically/terminally ill patients and their ranks?**

This question was directed to professional health care providers (see chapter 4, section 8.1).

TABLE 5.2 Results of a Chi-square test of association/relationship between professional health care providers' attitude and their ranks.

The professional Health care providers' attitude	Chi-square value	Degrees of freedom	Probability value
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The professional Health care providers' tend to be impersonal when dealing with the chronically/terminally ill patients.	10.87	6	0.09
Patients tend to be impersonal when dealing with professional health care providers'.	10.97	6	0.06
The professional health care providers' need to consider the cultural beliefs and practice of their patients.	12.26	6	0.06
The professional health care providers' do not know much about the patients' illness and refuse to listen to advice	14.27	8	0.07

This study found that there is a relationship between the professional health care providers and family care givers attitudes towards the chronically /terminally ill patients:

- The professional health care providers tend to be impersonal when dealing with the chronically/terminally ill patients. This was indicated by a Chi-square value of 10.868 (degrees of freedom = 6) with a probability value of 0.093.
- The chronically/terminally ill patients tend to be impersonal when dealing with the professional health care providers. Here a Chi-square:

Value of 10.972 (degrees of freedom = 6) was recorded with a probability value of 0.089.

- The professional health care providers need to consider the cultural beliefs and practice of their patients as indicated by a Chi-square value of 12.256 (degrees of freedom = 6) with probability value of 0.056.
- The professional health care providers do not know much about the patient's illness and refuse to listen to advice. Here a Chi-square value of 14.268 (degrees of freedom = 8) was obtained with a probability value of 0.075.

From table 5.2 the results of the chi-square test of association indicates a weak statistical association at 5% significance level. The association though stronger at 10% level of significance. That is to say the attitude of the professional health care providers does not seem to be affected by the rank of the professional health care providers.

- **Question 4: What support do the professional health care providers give to the family care givers of the chronically/terminally ill patients?**

The respondents to this question were the family care givers.

Of the respondents 14 (56%) were not told what the patients' diagnosis was, 19 (76%) of the respondents were not trained before the patients were discharged, 22 (88%) did not have their health status assessed before they adopted the care giving role, 20(80%) needed support in the areas of family, peer, religious, financial, medical supplies. Much as the family care givers needed services in home care the caregivers were neither told about the services available nor were the services made accessible to the caregivers and patients (see annexure 8a). This indicates poor discharge planning. People need to be told more about the care of their illnesses or that of family members, especially if patients are discharged before they are completely fit to take care of themselves at home.

Of the patients and the family care givers 50% indicated that they had problems in coping with HBC (see annexure 8a, 8b).

Hunt and Zurek (1997:320) stress that patients and family care givers feel confident when they know about their condition and their questions have been answered satisfactorily.

Question 5: Is there a difference between chronically/terminally ill patients, family care givers and professional health care providers level of satisfaction with home based care services provided?

All the respondents answered the question.

Table 5.3 The chronically/terminally ill patients, family care givers and professional health care providers' satisfaction with the home-based care services provided.

	Chronically /terminally	Professional health care	Family care giver
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	ill patients			provider					
	Mean	Std	N	Mean	Std	N	Mean	Std	N
Dependability of the professional health care providers	2.04	1.02	25	2.36	0.76	25	2.2	1.08	25
Consistency of professional health care providers visiting home	2.3	1.06	23	2.12	1.01	25	2.16	0.99	25
Frequency of home visits	2.8	0.93	24	2.04	0.84	25	2.29	1	25
Promptness of response to call by professional health care providers	1.96	0.89	25	2.38	0.97	25	2.17	1.03	25
Number of home visits	2.2	1	25	2.08	0.81	25	2.08	1	25
Quality of service	2.08	1.06	25	2.28	0.84	25	2.25	1.03	25
Assistance from others in caring for the patient	2.04	1.11	25	2.16	0.85	25	2.45	1.05	25

From table 5.3 on a scale of 1 to 5, with 1 indicating strongly disagree and 5 indicating strongly agree, the mean scores for chronically/terminally ill patients, professional health care providers and the family care givers is around the disagree mark which is level 2 on the Likert scale. This indicates unanimous dissatisfaction with home-based care services provided. The standard deviation likewise indicates similar perceptions for all the three groups.

5.2.6 Testing the difference between two means (t_{j^2} a m **unknown, but assumed equal**)

This test was used to show whether two different samples, in this case, chronically/terminally ill patients and the family care givers; the professional health care providers: and patients and the health care providers, came from populations having equal means. In other words, on average, there was no difference between

the way the professional health care providers (nurses) gave care and the way the patients perceived it.

The hypotheses for testing were:

1

$H_0: \mu_1 - \mu_2 = 0$ against

using a level of significance of $\alpha \sim 0.05$.

The null hypothesis stated that there was no difference between the means for chronically/terminally ill patients and that of the family care givers; the family caregivers and professional health care providers; and the patients and the professional health care providers, whilst the alternative hypothesis stated that there was a difference between the two.

The two-sample statistic for testing $\mu_1 \sim \mu_2$, assuming equal variances in the normal parent populations is given by:

$$t = \frac{(\bar{x}_1 - \bar{x}_2) - (\mu_1 - \mu_2)}{\sqrt{\frac{(n_1 - 1)s_1^2 + (n_2 - 1)s_2^2}{n_1 + n_2 - 2}}}$$

Where \bar{x}_1 is the mean of the family care giver, patient and the professional health care provider respectively.

s_1^2 is the variance for each group.

n_1 is the sample size in each group.

μ_1 is the population mean for each group.

The tabulated critical value for a two-sided t-test when the level of significance,

$\alpha = 0.05$, is $t_{\alpha/2, n_1 + n_2 - 2} = 1.708$. Therefore the ACCEPTANCE REGION = $[-1.708, +1.708]$

if the calculated value falls within this region, i.e. - 1.708 to + 1.708, then the null hypothesis is accepted, otherwise rejected. A comparable test is to reject the null hypothesis if the level of significance exceeds the p-value and accept the null if the p-value exceeds the level of significance. The rationale is that if the p-value is less than the level of significance, then the probability of observing an extreme value as the calculated one is small and in the critical region. This casts serious doubt on the validity of the assumption that the means were equal for the patients and family care givers; the family caregivers and the health care providers; and the patients and the professional health care providers.

There was no significant difference in the level of satisfaction between the three groups. This indicated that the professional health care providers the patients and family care givers were not satisfied with the quality of home care provided (see chapter 5, tables 5.3; 5.3.1) (Annexure 8c). Client satisfaction is assumed to reflect quality of care and is regarded as one of the outcomes of nurse client interaction.

This study found that there were major shortfalls in the quality of care rendered in Molepolole east. The follow-up of patients by professional health care providers was not as frequent as expected. Community health nurses very rarely went on home visits. The health workers who were seen occasionally were the family welfare educators. This was a disturbing situation as FWE's are employed to work mainly in the communities. The study found that they were seen more in the clinic at the expense of educating patients and their families in the community. However, the volunteers visited the families, but were less skilled to give guidance on HBC and chronic/terminal illnesses.

These findings contradict the Botswana government's goal to improve the efficiency and effectiveness of health care delivery, to ensure equitable distribution of services and to improve quality of care (Ministry of finance and Development Planning 1997-2003: 488:481).

The study found that the patients and the family care givers recognised that they needed assistance with famine/drought relief and it had taken over a year for some to get assistance and some were still waiting as the social worker was still assessing their eligibility to the destitute policy (see chapter 5, section 5.3.1).

Table 5.3.1 Differences in means between the patients and the family care

	Observed T-test statistic	Degrees of freedom	Conclusion
Dependability of professional health care providers	0.54	48	there is no difference in level of satisfaction
Consistency of professional health care providers visiting home	0.47	46	there is no difference in level of satisfaction
Frequency of home visits	0.75	46	There is no difference in level of satisfaction
Promptness of response of care giver/patient to call	0.76	46	There is no difference in level of satisfaction
Number of home visits	0.42	48	There is no difference in level of satisfaction
Quality of service	0.56	46	There is no difference in the level of satisfaction
Assistance from others in caring for patient	1.23	41	There is a difference in level of satisfaction at 15% level of significance

From table 5.3.1 the results of the t-test indicated that there is a no statistical difference in the mean scores of the patients and the family care givers in the home based care services provided. That is the patients and the family care givers' view the professional health care providers in the same negative way

	Observed T-test statistic	Degrees of freedom	Conclusion
Dependability of professional health care providers	0.54	48	there is no difference in level of satisfaction
Consistency of professional health care providers visiting home	0.47	46	there is no difference in level of satisfaction
Frequency of home visits	0.75	46	There is no difference in level of satisfaction
Promptness of response of care giver/patient to call	0.76	46	There is no difference in level of satisfaction
Number of home visits	0.42	48	There is no difference in level of satisfaction
Quality of service	0.56	46	There is no difference in the level of satisfaction
Assistance from others in caring for patient	1.23	41	There is a difference in level of satisfaction at 15% level of significance

From table 5.3.1 the results of the t-test indicated that there is a no statistical difference in the mean scores of the patients and the family care givers in the home based care services provided. That is the patients and the family care givers' view the professional health care providers in the same negative way

Table 5.3.2 Differences in the professional health care providers' and the patients' level of satisfaction with the home- based care provided.

	Observed T- test statistic	Degrees of freedom	Conclusion
Dependability of professional health care providers	1.26	48	There is a difference in the level of satisfaction at the 15% level of significance.
Consistency of home visits by professional health care providers	0.59	46	There is no difference in the level of satisfaction.
Frequency of home visits	0.16	47	There is no difference in the level of satisfaction.
Promptness of response to call by professional health care provider	1.66	47	There is a difference in the level of satisfaction at the 10% level of significance.
Number of home visits	0.47	48	There is no difference in the level of satisfaction.
Quality of service	-0.73	47	There is no difference in the level of satisfaction.
Assistance from others in caring for the patient	0.42	46	There is no difference in the level of satisfaction.

From table 5.2.3 of the two sample t- tests show that there is no significant statistical difference between professional health care providers and patients in the level of satisfaction with home based care provided at 5% significant level.

Table 5.3.3 Differences in the family care givers' and the professional providers' level of satisfaction with home-based care

	Observed T-test statistic	Degrees of freedom	Conclusion
Dependability of professional health care providers	-0.61	48	There is no difference in level of satisfaction.
Consistency of home visits by professional health care providers	0.14	48	There is no difference in level of satisfaction
Frequency of home visits	0.95	47	There is no difference in the level of satisfaction.
Promptness of response to call by professional health care provider	-0.72	45	There is no difference in the level of satisfaction.
Quality of home visits	0.11	47	There is no difference in the level of satisfaction.
Assistance from others in caring for the patient	0.02	43	There is no difference in the level of satisfaction.

There was no significant difference in the level of satisfaction between the patients, the family care givers and the professional health care providers with the home-based care services provided. This indicated that professional health care providers were not satisfied with the quality of the home care provided. The patients and the family care givers were also dissatisfied with the home-based care service provided.

- **Question 6 What are the patients and the family care givers¹ perceptions of the actual home-based care given, as well as the acquisition and utilization of resources?**

It was found that 14 (56%) professional health care providers said that patients utilised the available resources in home-based care while 10 (40%) said the patients sometimes utilised the available resources in home-based care, 12 (48%) indicated that the patients under-utilised home-based care resources as a result of lack of knowledge. Of the professional health care providers, 8 (32%) attributed under utilization of home care resources to culture/tradition. With regard to the quality of home-based care, 14 (56%) of the professional health care providers indicated it was good while 11 (44%) indicated it was fair. Of the professional health care providers, 14 (56%) indicated that patients should be readmitted whenever the family care giver was no longer able to manage.

The study found that of the professional health care providers, 14 (56%) indicated that the patients utilised available resources in home-based care, 10 (40%) indicated that they sometimes utilised available resources on home-based care, and 12(48%) indicated that they under utilised home care resources as a result of lack of knowledge. The family care givers, especially the elderly, had little or no knowledge of the disease of the relative for whom they were caring. Of the professional health care providers, attributed the underutilization of home care resources to culture/tradition (see annexure 8c).

Of the professional health care providers, 14 (56%) indicated that the quality of home-based care was good, 11 (44%) indicated it was fair, and 14 (56%) indicated that patients should not be re-admitted whenever the family care giver was no longer able to manage or supplies became inadequate (see annexure 8c).

At the same time, 20 (80%) professional health care providers reported that quality care was not accessible to all the people needing HBC in their catchment area while 16 (64%) indicated that the needed health services were not accessible to family care givers (see annexure 8c). The family care givers who indicated that the professional health care providers did not facilitate the accessibility of services endorsed this idea. However of the professional health care providers, 10 (40%) indicated that the time they were given was not adequate for home visits (see annexure 8c). This was similar to the perceptions of the family care givers and the patients who were not happy with the frequency of home visits (see annexure 8a and 8b)

This study found that 23 (92%) of the family care givers had their social life affected by care giving. This could be attributed to the fact that family members rarely participated in the care of the patient in HBC (see annexure 5). This study found that the professional health care providers rarely visited the patients in HBC (see annexure 6). Of the family care givers, 18(72%) indicated that they seek assistance from in the Family Welfare Educator. Of the family care givers 18(72%) had never been involved in decision making with professional health care providers. Nevertheless, the family care givers felt that they could recommend HBC to another person, because they perceived HBC as better than hospital care (see annexure 8b).

This study found that of the patients, 13 (52%) were discharged before they felt ready to go home, and 9 (36%) had either a nurse or medical doctor discuss their illness before discharge (see annexure 8a). This indicated that many patients are discharged without a professional health care provider discussing their illnesses. This has a bearing on how the patient and family care giver will cope in home care.

In Botswana the communities are composed of extended families therefore resources are shared communally. The whole family uses the rations given to patients. In order to fit the description of "destitute" a patient would not have a relative who can cope financially, according to the discretion of the social worker.

In some families the whole family depended on the PI00 pension that the grandparent received on attaining the age of sixty-five. This money is inadequate; it cannot cater for the needs of the whole family. The study found that some families that fitted the description of group A and B destitute were not beneficiaries of the destitute policy because they had been left out (see annexure 10). The machinery to select beneficiaries needs to improve otherwise the quality of HBC is compromised. The study found that the policy on destitute focused on individuals, yet some came from a poor families, the whole family that had problems, not the child or the mother as an individual (see chapter 5, section 5.3.2).

The health services need to be more sensitive to the needs of the worse off groups who have greater difficult making use of available resources. Poor people must be assisted by the government to attain a minimal standard of living. If people are as poor as indicated in this study, that they are not able to meet their basic necessities such as food clothing and blankets. According to the destitute policy these are the commodities given to all who are defined as destitute.

^^ The study found that when the nurses visited homes what care they gave was in terms of greetings patients and asking how they were and if families needed more materials. The nurse felt she was addressing patient's needs yet the patient felt very dissatisfied with the care provided.

Nurses valued their client care but it seemed they did not value what the patients wanted. In particular, nurses failed to take into consideration their own priorities for self-care. At times the nurses caused considerable inconvenience to patients because of erratic home visiting times. Sometimes the visiting health worker suggested treatment modalities which the patient and the family care giver considered to be insufficient or unnecessary. In home based care there has to be a match between the needs of patients and those perceived by professional health care providers (see annexure 8a).

The study found that access was a problem area. The patients and family caregivers indicated that HBC services were not accessible in terms of support systems, follow-ups, and resources (nursing) staff, money and materials (see annexure 8a).

The study found that the poor populations that needed supplies were not getting them, either because nobody told them about the services or no one made them available and accessible to them and their families.

The study found that the care given was not according to the expectations of patients and family care givers; information was scarce for patients and family care givers; and the resources were not used economically as those that needed them did not get them. For quality services to be given the customer and the professional health care provider must be in agreement that the care given addresses their needs. An effective skill mix is essential to provide quality HBC. Professional health care providers must be distributed among health facilities according to their preparation to give care that is acceptable in a community.

In order for HBC to meet the needs of the communities served, it must be relevant in the eye of those communities. Findings revealed that professional health care

providers did not pay much attention to what the patients and family care givers wanted. Comments and suggestions were ignored probably they were considered less knowledgeable on health issues (see chapter 4, section 5.4).

5.3 QUALITATIVE DATA

5.3.1 The family care givers

The researcher interviewed twenty-five family care givers. The analysis of the family care givers' responses revealed four main themes, namely, inadequate income, learning on the job, all alone in care giving, and lack of knowledge of services available.

5.3.2 Inadequate income to provide quality care

Of the respondents, 22 (88%) indicated a lack of income as the major impediment to providing quality HBC, The following were some of their comments:

Relatives and friends do give help once in a while but that is not enough, as someone cannot live from begging. There is nothing I can do to get money,

I would like to be given rations also. Only mother is given and I am also a mental patient and we do not have enough to eat. They should give us enough to feed us all. I do not work; nobody wants to employ us in our family.

We have been registered for over a year and are waiting for the social worker to come and assess us but she has not come yet. I hear she is very busy. The problem is that we have nothing to eat.

5.3.3 Learning on the job

When it came to family care givers receiving training before the patients were discharged into their care, generally the respondents indicated that they were not trained and had to learn what to do when the patients were at home already. For example:

Nobody has ever discussed the patients' illness with me, not even the treatment, as the card is lost.

The respondents felt that their needs were not met. For example:

I wish I could get assistance from relatives but no one seems to care. It is all my responsibility.

Unless we ask for help from the hospital, nobody says anything to us.

The patient is admitted for a drip and discharged on the spot even at midnight.

I find home better than in hospital.

This situation made family care givers feel frustrated and desperate for assistance.

5.3.4 Lack of knowledge of services available

The respondents indicated a lack of knowledge of services available in the community.

For example:

I do not know what services one can get in the community. The clinic staff has never told me anything.

I do not know about their service, as I do not need them. My daughter who died, last year did not die from HIV. She was bewitched. I will not get the milk for orphans for her 3 month-old baby that is for AIDS patients. As for my daughter who is also ill, I will struggle to support children.

5.3.5 Alone in care giving

Of the respondents, 22 (88%) family care givers felt that they did not get the support they expected from relatives and professional health care providers.

5.4 THE PATIENTS —

The patients interviewed were 25

All the patients remembered their unpleasant stay in hospital and would do everything possible to stay at home. For example:

I am satisfied with the care from my sister who cares for me alone. I have no children of my own. No other support. The hospital sent me home when I was still very ill

I wish they would remove the plate in my fractured thigh so that I am able to walk again. Nobody visits us from the clinic There is so much pain. I am just a cripple now.

I did not feel ready to be discharged home but I preferred to go, as the nurses did not assist much. They were reluctant to come when called. Relatives only give a bath when they come.

The clinic staff gets tired of listening. They want to tell us what to do. Why should they try to run our lives, they are not God?

From these responses it was evident that the patients were dissatisfied with the care provided by the professional health care providers. The health system does not meet the needs of the patients that they serve.

5.5 THE PROFESSIONAL HEALTH CARE PROVIDER

There were 25 professional health care providers that completed the questionnaire. The professional health care providers' responses revealed two main concerns or themes, namely reservations about the patients and family care giver involvement, and an inability to follow up on patients.

5.5.1 Reservations about patients/family care giver involvement

The following are some of the respondents' statements.

When it comes to readmission of patients, family care givers should be advised on how to manage conditions at home, not just bring the sick to the hospital.

There are many home-based care patients that make it difficult to admit to hospital all those who do not want to stay at home. Health workers are the ones to make decisions about readmission.

Relatives should be encouraged to care for their relatives at home.

The professional health care providers had problems with patients or the family care givers making decisions about their own health. The professional health care providers were comfortable with making the decisions.

5.5.2 Inability to follow-up on patients

The professional health care providers generally gave the shortage of personnel as the main reason for the failure to follow-up on patients. For example:

The home-based care team is active, but we at the clinic are not able to follow-up on patients, since we do not have adequate time to do so, other jobs at the clinic are time consuming.

There is a shortage of resources, e.g. manpower and transport to visit the client.

Lack of transport and manpower and time, for instance, a nurse or F.E.W. who is entitled to do home-based care duties spends most of the time doing clinic duties instead of home-based care as these patients need our support in the morning, for example, feeding, bathing, referring them for hydration.

Thus the professional health care providers confirmed the patients' and family care givers' statements that nobody visited from the clinic.

5.6 CONCLUSION

This chapter analysed the data collected from the patients, family care givers and professional health care providers. The data was presented in tables and graphs followed by discussions or explanations. It is evident from the results that the professional health care providers do not meet the needs of patients and family care givers. Patients as well as family care givers are not involved in the decisions of their care. Patients are discharged to homes where the family care givers have not been prepared to care for the person with chronic/terminal illness. As a result of that patients and family care givers become very dissatisfied with HBC. Very little or no support is available or accessible from the health workers.

Chapter 6 discusses the proposed care giving preparedness model.

CHAPTER 6

PROPOSED CARE GIVING PREPAREDNESS MODEL

6.1 INTRODUCTION

Chapter 5 discussed the data analysis and its interpretation. This chapter presents the proposed care giving preparedness model.

6.2 A CARE GIVING PREPAREDNESS MODEL

6.2.1 The scope of family care giving in home-based care

The home-based care programme in Botswana emerged as a result of the growing numbers of chronically/terminally ill patients. The family members are the key players in providing invaluable care to the patients that live in their households. Whilst nurses and family welfare educators did follow-up patients in HBC the visits were found inadequate and ineffective hence the approach of utilising family members and making them adopt a more prominent role. It is crucial for the health care system to provide adequate support for the family care givers in order for them to develop the desired competence in the care-giving role.

As the families become increasingly responsible for persons, chronically/terminally ill, interventions to assist them must have a theoretical basis. Formal knowledge development can make explicit the nature of family care giving competence, lay the foundations for a more systematic approach to clinical care giving competence and make possible research in which care giving is a variable (Brereton and Nolan 2000:499). In this regard a model that prepares family care givers for the care giving role is essential.

6.2.2 Rationale for the model

This model arose from a concern expressed by the family care givers in this study that they had little or no support from professional health care providers and that they were never trained to give care. Furthermore, the researcher had worked in the community for over ten years as a lecturer in community health nursing and was familiar with the health care system. While following students on home visits the researcher found that patients that were chronically/terminally ill were not receiving the best care from health care providers. Family care givers tried their best to care for patients but because they lacked nursing knowledge their efforts were futile.

In developing the model, the researcher also took into consideration the literature reviewed and the findings from this study, integrating the various responses to conceptualise the effective care-giving model.

The Ministry of Health's training manual, modules on home-based care for training of trainers (2000c: 10) states clearly that assessment of clients' health status and needs for care, counselling and support is necessary in home care nursing. No mention is made of assessing the family care giver's needs prior to adopting home- based care. In situations where no assessment was made, the family care givers might prove unable to render care at the expected level because of various reasons. In the context of this model an assessment of patients and family care givers' abilities in HBC is essential.

The literature review indicated that in order for care givers as well as the professional health care providers to be effective, there is need for education and training in the following areas: the care giving role, support during care giving,

the patients' illness and the care givers' own health. Chapter 3, section 3.7 stressed the need to train family care givers.

Without the support of family members, it would be impossible to have patients cared for at home. The family care givers are expected to transform themselves into health care para professionals without preparation at the time the patients are discharged home. The family care givers have to take over the roles of all health care providers such as the nurse, physician and others. Because the care-giving role is so comprehensive, the family care givers mostly find themselves ill prepared to cope with tasks expected of them.

The Scottish Livingstone Hospital in Molepolole (1997:6) reported that family care givers were reluctant to keep very ill persons at home; they preferred them to be hospitalized despite counselling of relatives. What exactly this counselling comprised and what the family care givers' perceptions of the interaction with these professional health care providers were needed to be determined. This interaction determines the family care givers' contributions to decisions on the patients's discharge and care.

The Scottish Livingstone Hospital (1997:7) reported further that there was a lack of family support for chronically/ terminally ill patients, especially those with mental illness, and this accounted for relapses. There is a stigma attached to mental disorders in the Botswana community.

Some family care givers find themselves compelled by circumstances beyond their control to provide home-based care. In a study addressing factors associated with hospitalization at Lobatse referral mental hospital in Southern

district, Botswana, Monggae (1993:3) found that communities lacked knowledge on the behavioural changes and management of psychiatric patients. The illness was stigmatised and relatives would rather have family members spend a lifetime in a hospital than care for them at home.

Ideally, community home-based care should enable chronically/terminally ill patients to be cared for in their own homes, make their own choices and live their lives with the acceptance of the local community. In Botswana there is a growing population of chronic mental patients requiring long-term care. Community mental health care[^] implies a reliance on informal support networks, which cannot always be guaranteed. A model to prepare family care givers becomes essential.

6.2.3 Preparation for home based care

Chronically/terminally ill patients are most often discharged into the home-based care of the relatives whom they were staying with before being admitted to hospital. How well prepared the family members are before taking up care giving remains an area of concern. Discharging patients to family members does not make those members competent to render care if they are incompetent.

The success of a home-based care programme is dependant on how the health professionals prepare patients, relatives as well as significant others at the time of discharge. A comprehensive health assessment of the family into which the patient is to be discharged is of paramount importance.

In chapter 5, findings indicated that the family care givers reported that the professional health care providers had not given any instruction about how to

perform any of the activities of care for the chronically/terminally ill persons. The family care givers needed to discuss how to access HBC resources. Chapter I section 1.7 emphasises that the family care givers adopted the care giving role without any preparation and not knowing what they were doing.

The study found that the patients and the family care givers were not satisfied with the care they received from the professional health care providers as they were not actively involved in the decisions on the care that affects them (see chapter 5, section 5.3.4; 5.4).

In developing the model, the researcher took into consideration the following principles of teaching:

- Adapt the teaching to the clients' level of readiness.
- Determine the client's perception of the subject.
- Ensure a conducive environment to learning.
- Involve the clients throughout the learning process.
- Make subject matter relevant to the clients' use and interest.
- Ensure client satisfaction during the teaching learning process.
- Provide opportunities for the clients to apply material into practice

The researcher also took the following principles of learning into account:

- Consider clients' experience and give client frequent feedback.
- Cater for the clients' level of understanding.
- Create a conducive environment.
- Encourage the client to participate in goals, need assessment, evaluation, and learning process.
- Motivate the clients to learn.
- Help the clients to progress toward the goal.

- Integrate learning through application.

Family care givers must take responsibility for their learning.

The researcher adopted a systems approach to the study in order to determine health problems of patients and family care givers of the chronically/terminally ill patients. The systems thinking according to King can be grouped into three interacting systems that is personal systems (individual), interpersonal systems (dyads, triads, groups), social systems (family, schools, social organizations, and health care system).

In her systems framework for nursing, King (1995) views family members as complex subsystems interacting with the environment. Health care systems are open, and professional health care providers are subsystems that interact with the family members and the chronically/terminally ill. This approach emphasises complex family interactions between personal, interpersonal, and social systems.

In the current study, "family" embraces not only blood relatives but all significant others involved in care giving (see chapter 1 section 1.10.) The systems approach views the patient and the family care giver holistically as a whole system with interdependent parts. The system and its parts have structure and functional components (see chapter 2)

In summary human beings are open systems in constant interaction with the environment. Nursing focus is people interacting with the environment. The goal of nursing is to help individuals and groups to maintain health.

6.2.4 The aim of the model

The overall objective of the study is concluded in this chapter, by the conceptualisation of a nursing model encompassing an adult education approach in training family care givers in HBC. The aim of the model is also to foster creativity in professional health care providers that will enable them to be innovative and creative health providers in facilitating effective education of family care givers. It is important for the health care system to develop capacity among families for providing and sustaining comprehensive care and support for the chronically/terminally ill patients.

According to Wright (1990:3-4), a nursing model is a collection of ideas, knowledge, and values about nursing that determine the way nurses work with their clients. A model represents aspects of the real situation. In this instance, this was the need of the family care givers denoted by a deficit in terms of training. Information was lacking as far as their key functions were concerned. Slevin (1995:199-200) points out that a model reflects an attempt to provide a general conceptual framework that, in turn, enhances an understanding of the situation and guides practice within the framework. A model must define what to do, how to do it, and how to assess it Wright (1990:3-4).

6.2.5 Propositions

The following are the propositions of the care giving preparedness model. These propositions encompass all the concepts of the model discussed below.

- individuals are unique and respond differently as they interact with their environment. The health care providers, patients, family care givers and the health care system are in constant interaction. They all affect and are affected by the other.
- in purposeful interactions the nurse assists client to solve health problems as they occur

- Human beings are universally caring and are capable of being concerned with needs of others. Care giving occurs through interaction.
 - nurse -patient interactions result in mutually agreed goals for the good of all when goals are achieved
 - goal oriented interactions enhance effectiveness and create positive outcomes
- Interaction is relevant and interdependent to all the concepts discussed below.

6.2.6 Major concepts of the model

- **Interaction**

Froman (1995:225) refers to the interaction between patients, family care givers and professional health care providers to determine goals and the means to achieve them as transactions. Part of the interaction (transaction) is the exchange of information in order to ensure an acceptable level of care, verify the accuracy of the information, and assess the situation. Thereafter solutions to the problems can be worked out. In an interaction between health care providers, patients and family care giver each person is influenced by their own values that they bring into the situation. Past experiences and mechanisms for human interactions are brought to play. Interaction is essential in the care giving preparedness model as communication has to take place between the nurse and client be it verbal or non verbal.

- **Care giving**

In this study, care giving means the provision of home health care which includes specific caring characteristics such as good mood, understanding, genuineness, patience, respect, giving emotional support, listening, giving hope, spending time, physical support, giving advice/information and co-ordinating services (McQueen 1997:334). For family care givers to exhibit such characteristics, the environment must be supportive to home care giving. Family care givers must function within an environment that is conducive to learning new behaviours. They must feel free

to participate in the decision making process of their health care. Adequate training imparts essential skills and competences in patients and family care givers.

The family care givers in this study were considered providers of care to patients for the time that they were looking after a chronically/terminally ill relative. The family care giver might not have had prior knowledge or experience of looking after a chronically/terminally ill relative. This would make the type of care given haphazard and poor hence the need for increased support from professional health care providers. Right from the onset of adopting the care giving role the family care needs to be involved in decision making processes of her care. Family care givers and health care providers have to mutually agree on the goals of nursing care.

Care giving for chronically/terminally ill patients makes great demands on professional health care providers and family care givers. Usually nurses play a major role in helping families bear the burden of living with persons who are chronically/terminally ill. One of the main aspects of being a nurse, then, is interacting with the family, which should result in a close relationship between the professional health care providers; the patient and the family care givers. At times, however, this interaction does not happen.

The concepts of caring, care giving, and interactions between the patients and the professional health care providers were dealt with in chapter 1. This motivated the researcher to develop a model that could be implemented to effectively prepare family care givers for the care-giving role.

- **Nursing process**

The nursing process in this model is used as the vehicle for the delivery of HBC. Nursing functions are conducted within the context of the nursing process. Pearson and Vaughan (1990:129) point out that the nursing process is an "interactive process of action- interactive - reaction - transition".

According to Leddy and Pepper (1998:170), using the systems theory to guide the nursing process directs the assessment of the nurse-patient interaction or relationship. The steps in the nursing process are discussed below.

- Assessment

An assessment is a systematic collection and orderly collection of data from clients. Meleis (1997:341) states that King's theory is useful for assessing individuals and group relationships in nursing. It can then be concluded that the systems framework is an appropriate tool for assessing the community. Leddy and Pepper (1998:220) emphasise that assessment "incorporates perceptions, communication and interaction of the nurse and client".

An assessment of both the patient and family care givers' needs determines whether the family care givers have the ability to take up the care-giving role or not. A comprehensive assessment is the cornerstone of good practice in the health and social care of chronically/terminally ill patients including their family care givers. The quality of that assessment and subsequent action is a key factor in determining the outcome of home care.

The systems approach enabled the researcher to take a holistic view of the clients, families and communities and their environment. This makes it possible to assess how the families function and how the interaction between family

members affected each other. An assessment occurs during an interaction of the nurse and the client, family care giver. The patient, family care giver brings into the situation knowledge of self-perception of the problem that is of concern. In this instance care giving of a relative or a friend the health care provider brings special knowledge and skills.

- Nursing diagnosis

Nursing diagnosis may be defined as the identification of human responses and resource limitation; it also reflects client concerns and disturbances in health. Nursing diagnosis also indicates the nurse's understanding and analysis of the patient's social systems, perceptions, interpersonal relations as well as coping with feelings of dependency. Leddy and Pepper (1998:16) state that interacting models emphasise social acts and relationships between people. In this case nursing diagnosis can be considered to be a decisive statement about the needs of patients or family care givers in HBC.

- Planning

Planning may be defined as the determination of what shall be done to assist the patient or family care giver of the chronically/terminally ill patients. In this stage of the nursing process, the nurse and the client set goals and agree on the means to achieve them. In the home-based care situation, the professional health care provider (nurse), the family care giver and the chronically/terminally ill patient plan together.

- Implementation

After planning procedures and setting the goals for the care of the chronically/terminally ill, the parties concerned start implementing the programme in order to achieve the goals they set. The professional health care

provider considers various actions, selects those suitable to achieve goals and objectives.

- Evaluation

This is the appraisal of patients /family care givers behavioral changes due to the actions of the professional health care provider. The key to appropriately evaluating nurse/client actions lies with the plan when objectives are clearly stated in behavioral terms with clearly stated outcomes. This stage evaluates how effectively the home-based care programmes are implemented. The effectiveness of the programme is also assessed and/or whether they need to be changed. Just as the goals and objectives should be mutually agreed upon by the nurse-client it is important that the client -nurse sets criteria for evaluation.

- Input in a systems model comprises the elements that move from the environment into the system. The patients and family care givers are the input entering the health care system from the community, which is the environment. Resources for HBC are also defined as inputs into the health care system.
- **Process** is a set of inter-related resources and activities, which transform inputs into outputs; it consists of those acts, done to or with input, namely the policies and procedures that regulate care giving in HBC. The process in this study is the programme designed, including all the stakeholders, to prepare family care givers for HBC. This process is the means to transfer goals and ambitions to ends.

- **Output** is a product of the system. In this instance, the patients who are satisfied with the care given in HBC and the family caregivers who are trained to provide effective care are the output.
- **Feedback**
A series of output and inputs across the system - environment boundary is called feedback. In this model feedback must be established between the patients, family care givers and professional health care providers. Performance appraisal is the feedback loop that finally designs alterations in the system. A complete feedback has three components, namely measurement, judgment and alteration. In this case, it is the training given to family care givers, which should satisfy the patients if it is effective. In this instance the family care givers will evaluate their relationships with the patient or professional health care providers and their competence in performing care-giving tasks. The expectations are the criteria against which the care is measured. Evaluation also means determining whether the training objectives are met and removing obstacles. It is not enough to train the family care givers and not eliminate the shortfalls of the programme.

6.2.7 Structure and context of the model

This section represents the proposed model. George (1990:5) states that a model is a pictorial representation of a proposition. In it a variety of diagrams, shapes and arrows are used to show relationships and interactions between the various concepts. The data analysis was used to conceptualise the clinical phenomenon of effective care giving in the context of this study. The ultimate aim of the concept development was to lay the foundation for assessing family care givers' competence in the role of care giving. The data assisted the researcher to conceptualise the

model that could be utilised in the training of family care givers, patients, and professional health care providers in providing care in the context of HBC.

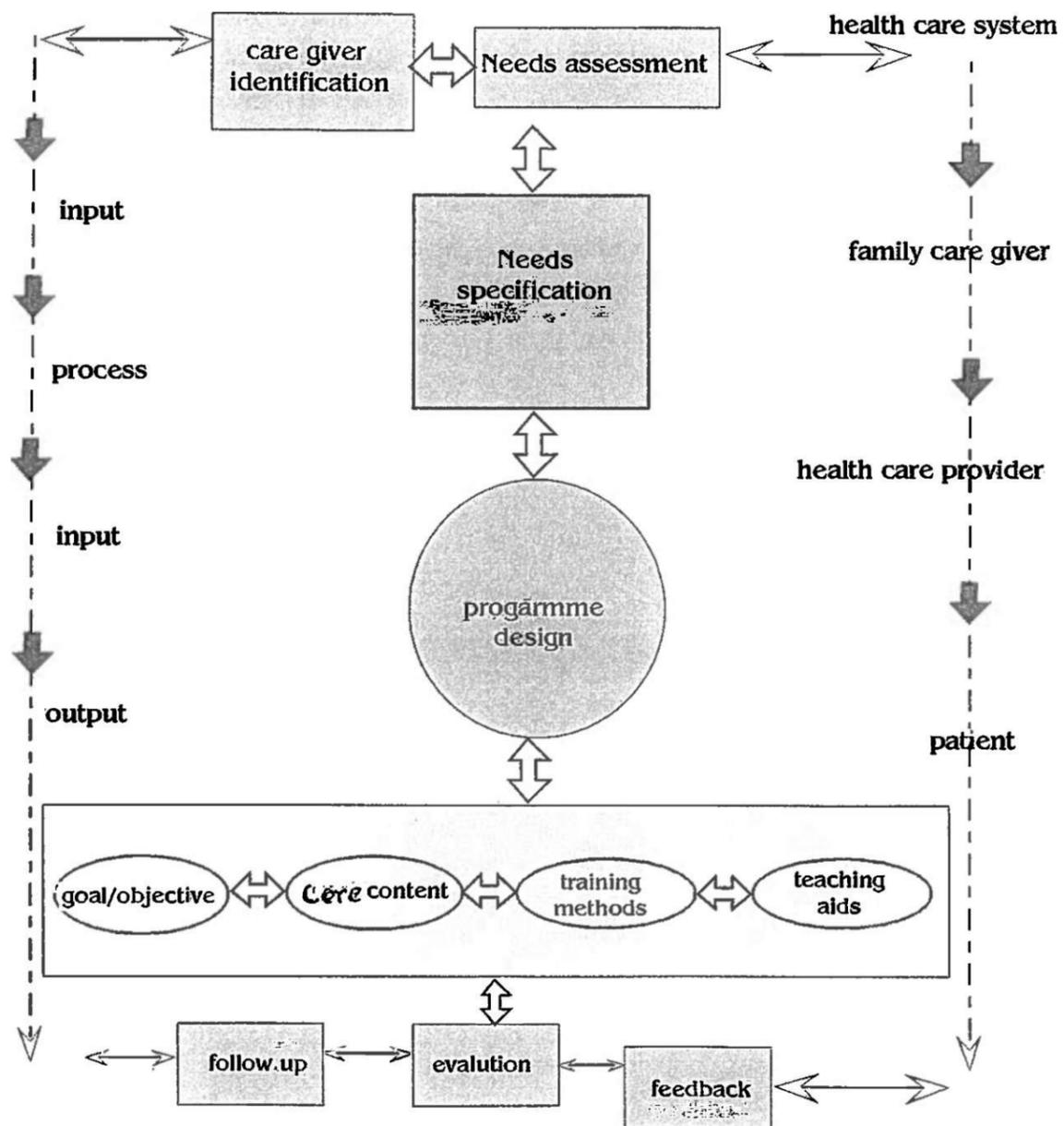
The model portrays the elements that are essential for effective care giver training, namely

- Identification of family care givers, depicted by the top rectangle
This is the initial consultative/interactive process between the patients and family care givers, collaboration between the client and the professional health care provider.
- The needs assessment stage of patients and family care givers is represented by the second rectangle
- The specification of training needs is represented by the square in the middle of the diagram
- The development of the care giving training programme and implementation, including contributions from all participants, is represented by the big circle.

The objectives and goals of the training programme are defined as well as the core content; training methods and teaching aids are mapped. These are represented by four circles in within a large rectangle.

- The feedback loop, is depicted by the rectangles at the bottom of the model which includes
 - Evaluation
 - Follow up/monitoring
 - Establishing mechanisms, all these are represented by the bottom rectangles
- Input, process, output are shown by the arrows
- Connecting arrows indicate the relationships between the patient, family care giver and the professional health care provider.

Figure 6.1 diagrammatic presentation of the care giving preparedness model

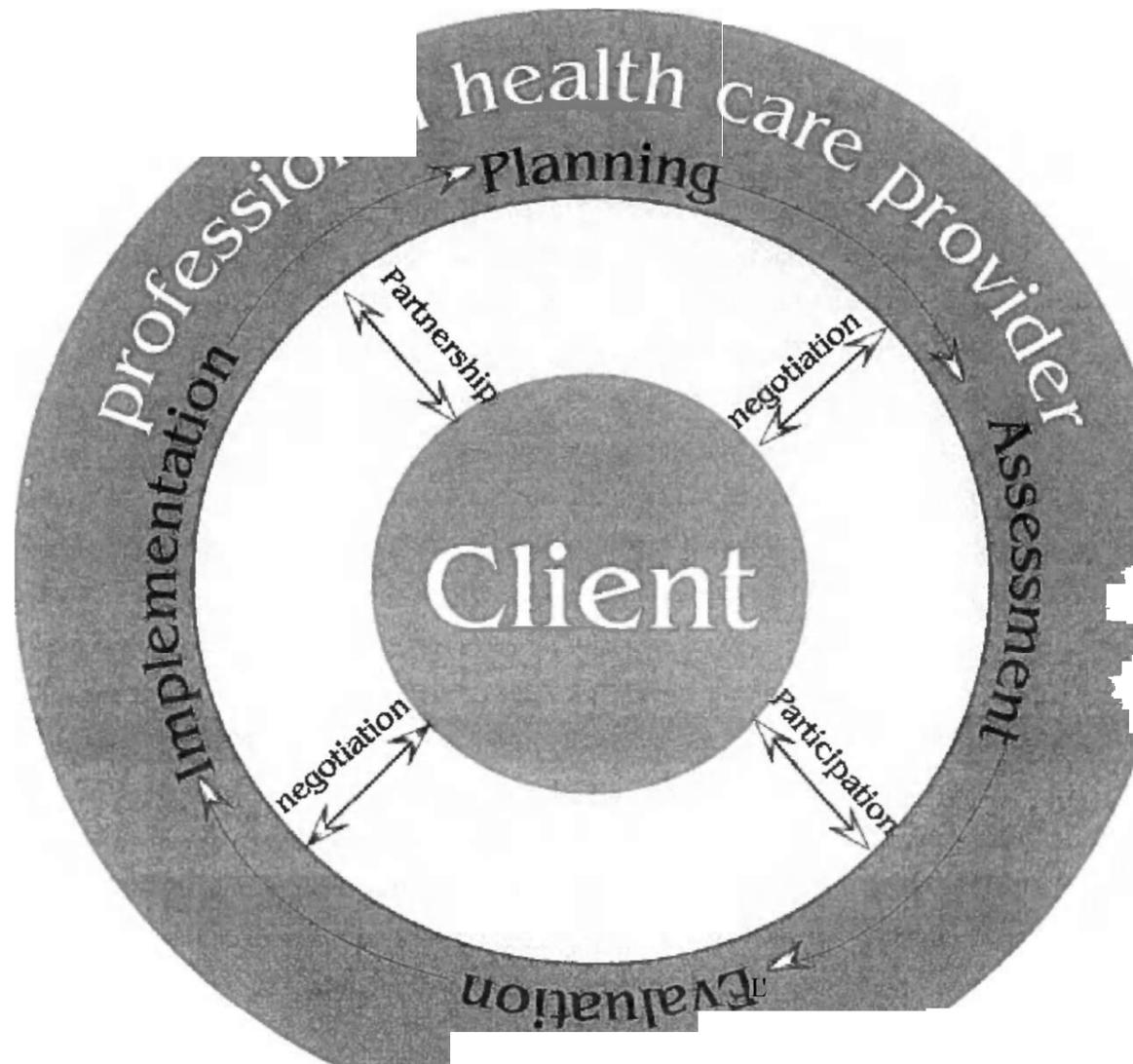


This model is applicable to patients, family care givers and professional health care providers. These people require training in care giving. The proposed model emphasises the three systems, that is the personal, interpersonal, and social system interacting with the environment.

- **Identification of the family care givers**

This is the first stage of the care giving preparedness model, when the professional care providers establish a dialogue with the client. This partnership has to be mutually agreed upon by the family care giver and the patient. Figure 6.2 below depicts the stages of the dialogue.

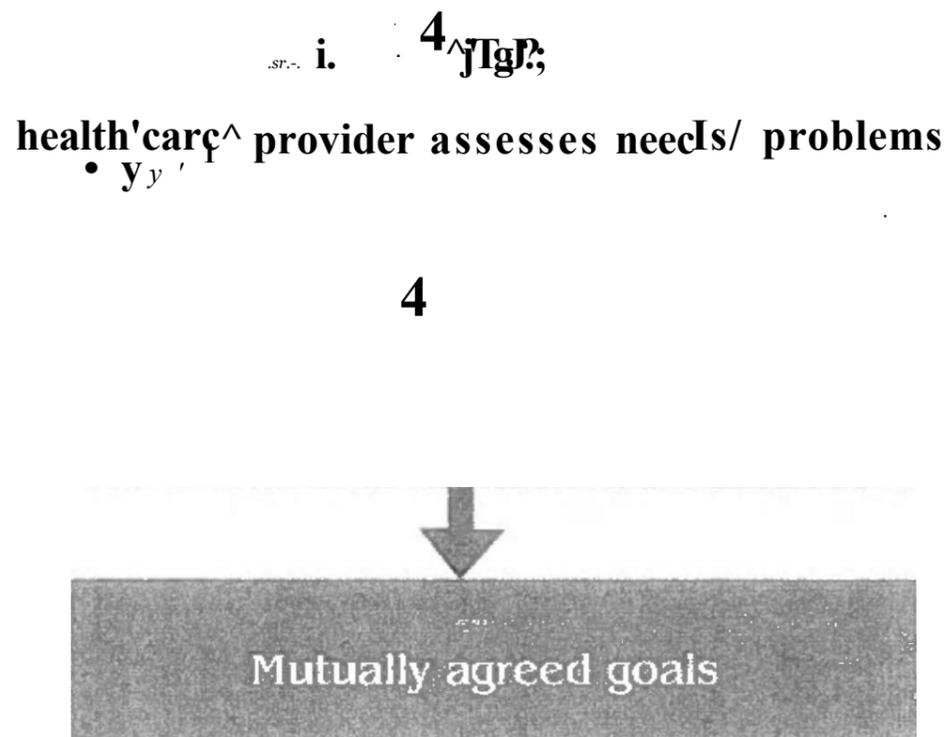
Fig 6.2 stages of the dialogue



The above features form the basis of a reciprocal relationship between the nurse and the client. The process aims at meeting the needs of the client based on agreed goals and objectives. This is the initial consultative/interactive process between the patients and the family care givers. At this stage it is important to establish collaboration between the client and the professional health care providers. Allender and Sprandley (2001:140) define collaboration as a purposeful interaction between the client who is either the patient or the family care giver, based on agreed values, mutual participation and joint effort. Consultations between the family care giver and professional health care provider is needed so that the two groups understand each other's values, philosophies, and objectives. The relationship developed is dynamic and aimed at fulfilling client's needs. All parties must be clear on what their roles and responsibilities are in the relationship (see chapter 2, section 2.5.2).

The professional health care provider needs to collect pertinent data on the family care giver's attitude, willingness and readiness to be a care giver, the health needs of the family care giver, and the ability to provide care. This is to determine the eligibility of the family care giver to participate in care giving. The family care giver needs to indicate willingness to participate in this role and the health status of the care giver needs to be assessed as well (see chapter 1, section 1.3.7). Figure 6.3 below illustrates the needs assessment process as part of the care giving preparedness model.

Figure 6.3 need assessment process



George (1995:223) points out that assessment occurs during the interaction of the nurse and the client. The nurses bring expert knowledge and skills while the patients bring knowledge of themselves and perceptions about the problem. According to Ruppert (1996:41), the emphasis is on the involvement of family care givers in the assessment of their needs and programmes. Therefore, for training of family care givers to be effective, the professional health care providers need to conduct a needs assessment of clients, by collecting pertinent data on the family care giver's knowledge, skills, attitude, health status and ability to provide care for the patients. In this assessment the family care givers need to be consulted by the professional health care providers as equal partners.

- **Specification of training needs**

Sato et al (1998:71) states that family care givers have unmet needs that need to be addressed by designers of any training programme. At this stage the training needs are specified after the analysis of information collected from the family care giver. The diagnosis is made to determine the clients' present status and identify training needs. At this stage, standards and procedures for training programme should be established.

6.2.8 Design of the care giving preparedness programme and implementation

After the broad problem areas are identified, the programme goals and objectives are marked out. The core content of the training programme is spelled out, that is the competences, skills, knowledge and support needed. The training techniques must be determined such as problem-based learning and integrated learning and materials that include practical demonstrations and visual aids. The patients, family care givers work together in achieving objectives.

It is important at this juncture to also establish mechanisms to ensure continuity for those contributing to the training programme. The learning experiences should be carried out as planned. The plan should meet the objectives of the family care giver and professional health care providers.

This study found that the professional health care providers need to assess multiple care giving processes and target interventions to processes with which the family care givers need help.

The literature review indicated that in order for care giving to be effective, the family care givers' needs should be assessed and met.

- **Feedback**

Feedback is the flow of energy between the system and environment. A series of output and inputs across the system - environment boundary is called feedback. (Fawcett 1989:112). In this study the systems which are the patients, family care givers and the health care system are affected by and in turn affect the environment. While affecting the environment, a process we call output, systems gather information about how they are doing. Such is fed back into the system as input to steer its operations. Feedback must be established between the patients, family care givers and professional health care providers. Performance appraisal is the feedback loop that finally designs alterations in the system. Feedback of outputs into the inputs makes the system self-regulated. It is through feedback process that the open systems interact with their environments

A complete feedback has three components, namely measurement, judgment and alteration. In this case, it is the training given to family care givers, which should satisfy the patients if it is effective. In this instance the family care givers will

evaluate their relationships with the patient or professional health care providers and their competence in performing care-giving tasks. The expectations are the criteria against which the care is measured. Evaluation also means determining whether the training objectives are met and removing obstacles. It is not enough to train the family care givers and not eliminate the shortfalls of the programme.

- **Monitoring/follow up**

This study found that the patients expected follow-up from the professional health care providers after discharge from hospital but did not get that assistance. Through follow-ups, the professional health care providers can assess how the family care givers are coping with the care giving activities. There is a need to assess whether change has taken place. The time to measure progress towards goal achievement must be mutually agreed upon by all the parties, including methods used. The patients, family care givers and professional health care providers must also mutually agree on the frequency of follow-ups.

The arrows on the diagram represent how input, process and output takes place in the systems approach.

Input in a systems model comprises the elements that move from the environment into the system. The patients and family care givers are the input entering the health care system from the community, which is the environment. Resources for HBC are also defined as inputs personnel, finances, facilities, equipment, techniques and methods.

Process can be seen as means that can be used to meet the overall objective in this instance HBC. These means can be related to technical or operational

conditions and consists of those acts, done to or with input, namely the policies and procedures that regulate care giving in HBC. The process is the programme designed, including all the stakeholders. A process is goal oriented and systematic that is the activities that make a process are interrelated and interdependent. During the process evaluation criteria are determined and agreed upon by the patients, family care givers and health care providers. In documenting the process flow charts and verbal descriptions are used commonly.

Output is a product of the system. In this instance, the patients who are satisfied with the care given in HBC and the family caregivers who are trained to provide effective care are the output.

6.2.9 Conclusion of the model

A description of the care-giving model for the training of family care givers marks the consummation of this research study. The study presents a challenging, new approach to health care providers. It is hoped that the professional health care providers will empower the family care givers with the necessary knowledge and skills that will enhance the chronic/terminal ill patients' satisfaction.

6.2.10 Evaluation of the model

The researcher adopted an analytic approach, to develop the model. The researcher evaluated the model according to the criteria of clarity and consistency, generality, practicability, flexibility and adaptability, and appropriateness.

- **Clarity and consistency**

The concepts should be clear and consistent. In the model, the researcher tried to avoid unnecessary repetition in the explanation of concepts. To enhance clarity and understanding, the model use diagrams and illustrations.

- **Generality**

The model must be general enough to be used in a variety of settings rather than one particular setting. This model is capable of laying a foundation for nursing research, and can be applied to individuals, families and communities.

- **Practicability**

The model can be implemented immediately as there are no cost implications. The model is useful because it enables the professional health care providers to consider a variety of factors, and emphasises partnership with all the relevant stakeholders. Participation is necessary from all concerned so that the goals are mutually agreed upon.

- **Flexibility and adaptability**

The model can be used in various settings in HBC. The patients, family care givers and professional health care providers can use it for teaching, administration and clinical practice.

- **Appropriateness**

This model is intended for a specific target, namely the patients and family care givers and professional health care providers. The model has a defined process of assessment to determine the problems. Cooperation between the patients and family care givers is encouraged to solicit input from the professional health

care providers. Clients are to make informed decisions on the type of HBC provided.

6.3. IMPLICATIONS FOR NURSING

The study found that many elements of HBC already exist in Botswana as the families are extended. Therefore, the extended family is the greatest resource of support for chronically/terminally ill patients. The HBC model in Botswana places the main responsibility for care on the family care giver, supported by the professional health care provider. In view of the above, the nursing implications are as follows:

6.3.1 Information sharing

The study found that many family care givers adopted the care-giving role without preparation. The family care givers did not have basic information to equip them with skills to provide quality care. It is important for the professional health care providers to recognize and become aware of the different coping strategies that families use. This is important so that nursing interventions are geared to the needs of patients and family care givers. Information on their condition is vital in the care of chronic/terminally ill patients. Thus the information must be clear, honest, factual and use simple language that is non-technical. Lack of information contributes to frustration and anxiety among patients and their family care givers. The diagnosis and other vital information must be shared with patients and family care givers. There is a need to design training programmes that deal with and meet the needs of family care givers and the patients.

6.3.2 Access and availability of professional health care providers

Professional health care providers exist in any community to provide the necessary support to patients and families. The support should be available as determined by the patients and family care givers, not the professional health care providers. With the increase of chronically/terminally ill patients, resources have become and are scarce, including professional health care providers. Community health nurses should lead in assisting patients and their care givers to cope with the stress of long-term care. Continuity and comprehensiveness of care depends on the accessibility of nurses in the community on a 24-hour basis. In this study, nurses were found to be scarce when it came to home visits. Home-based care has been delegated to those with less training, like FWEs and volunteers. Patients were very dissatisfied with the quality of home visits conducted by nurses. The visits were sporadic and hurried with a few words of greeting exchanged and an inquiry of what the family was running short of. There was no time to discuss issues pertaining to the patient's and the family's general welfare. Patients and families need quality time with nurses in the community.

6.3.3 Resources

The majority of the respondents were from low-income family groups. Basic commodities of daily living were not available in some families. The respondents were either permanent or temporary destitutes according to Botswana standards (see annexure 10). The role of the professional health care providers was to facilitate acquisition of resources for all those in need. In this study people in need of resources often waited a long time before being approved as eligible for destitute rations. The reasons for the delay were that they were not told about the resources, or the resources were not accessible to them.

6. 3.4 Level of participation

The study found that the level of participation was not satisfactory in the view of the patients and the family caregivers. The findings indicated that the rights of the patients and family caregivers were not considered in a health care system.

6.4 CONCLUSION

This chapter summarised and interpreted the data collected in this study. The researcher applied the data in the development of the care giving preparedness model. Chapter 7 concludes the study and makes recommendations for further study.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

7.1 INTRODUCTION

This chapter discusses the limitations of the study and makes recommendations to improve HBC and for further study.

7.2 CONCLUSIONS

The study aimed to

- determine the accessibility and availability of HBC services in Molepolole East, in the Kweneng health district, Botswana
- investigate how family care givers, patients and professional health care providers viewed and experienced Botswana home care
- determine the roles played by professionals, patients, care givers and their relationships in the context of home-based care
- make recommendations for the improvement of home care nursing and for future research
- develop a model to prepare home care givers

All the objectives of the study were achieved.

The study found that

- needed health services were not available and accessible to a majority of patients and family care givers.
- patients and family care givers were dissatisfied with the quality of care provided in HBC
- professional health care providers made decisions for patients and family care givers without involving them

- professional health care providers were not supportive to patients and family care givers as they were reluctant to respond to calls when requested.

The data that was collected and analysed in this study answered the research questions. The researcher then concluded the following:

- (1) Although the family care givers are the key players in the provision of HBC, their needs are not known nor catered for by the professional health care providers.
- (2) The interaction between the professional health care providers and family care givers does not yield very satisfactory results, as the family care givers are usually not adequately prepared for their role. There is a need to train family care givers and give them the necessary information on the patients' condition the treatment and how to access the necessary resources.
- (3) At present it is possible for CHNs in Botswana to lead the improvement of quality in HBC services. Currently the Botswana government provides adequate resources to cater for the needs of all, provided they are shared equitably.

7.3 LIMITATIONS OF THE STUDY

This study had several limitations. The sample was small. A larger sample would have increased the confidence of the findings. A convenient sample was used and may not represent a typical sample of chronically/terminally ill patients and their family care givers. In this case caution should be used in generalizing the findings to a larger population. The study did not cover the whole of Molepolole, but only a small portion. Due to the non-probability sampling method, generalization to all patients, family care givers and professional health care providers cannot be made. However, the findings can serve to increase the awareness of policy makers and professional health care providers to some of the needs of family care givers of chronically/terminally ill patients.

The respondents were mostly female patients and family care givers. The majority of participants came from low-income families. Higher income clients would not have the same problems of poverty.

The time allocated to data collection was only five months, which was too short for a comprehensive search for answers to the research questions. The use of FWEs and clinic registers to identify patients limited the sample by excluding chronic/terminal ill patients who had never been at the health facility. Social workers were not willing to participate in the study. It would have enhanced the results had they answered the research questions like the other professional health care providers.

1

7.4 RECOMMENDATIONS FOR IMPROVING HBC

The researcher identified weaknesses and gaps in the care provided by family care givers to chronically/terminally ill patients and makes following recommendations to improve the quality of HBC:

- (1) Educational programmes designed for home-based care should be sensitive to the needs and situation of the clients.
- (2) An effective skill mix is essential to provide quality HBC. Professional health care providers must be distributed among health facilities according to their preparation to give care that is acceptable in a community and facilitate adequate supervision in HBC services.
- (3) Assessment of eligibility for HBC resources should be done by community health nurses as well as social workers.
- (4) The proposed preparedness care giving training model should be considered for training for patients and family care givers before discharge and during HBC.
- (5) Increase the level of participation in decisions on their care by patients and family care givers. This should be done by setting mutual goals and objectives and agreeing on needs identified. Family care givers need to have a comprehensive

health assessment at the time of patient discharge. The values and beliefs of patients and family care givers need to be taken into consideration.

- (6) Government and non-governmental organisations to establish support groups to assist patient's family care givers and health care providers in the care of chronically/terminally ill persons in HBC such as respite care and old people's home.

7.5. RECOMMENDATIONS FOR FURTHER RESEARCH

The researcher recommends the following areas for further research:

- (1) Community health nurses should conduct studies to assess the effectiveness of the HBC programme in Botswana.
- (2) A replica of the same study is necessary on a larger scale to be more representative of the population of chronically/terminally ill patients and their family care givers.
- (3) The needs of chronically /terminally ill patients and their family care givers should be researched.

7.6 CONCLUSION

Home-based care can only materialise through the participation of family caregivers. There is a need for active involvement in the assessment, planning, implementation and evaluation of the training programme to improve the competence of family care givers. HBC services should be accessible by means of support systems, follow-up visits, and other resources.

The study found there were major shortfalls in the quality of care rendered in Molepolole East. The researcher assessed how the resources were distributed in the community among the chronically/terminally ill patients in HBC. The care provided should address the needs of the patients and family care givers. The study

found that the care given did not meet the expectations of the patients and the family caregivers. For HBC to meet the needs of the communities, it must be relevant in their view and meet their needs.

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ANNEXURES

Annexure 1 Permission from Office of the President

Annexure 2 Letter from District Commissioner

Annexure 3 Letter from Scottish Livingstone Hospital

TELEGRAMS: PULA
TELEPHONE: 350800
TELEX: 2655 BD



REPUBLIC OF BOTSWANA

OFFICE OF THE PRESIDENT
PRIVATE BAG 001
GABORONE

OP 46/1 LXXXIV (21)

26 September, 2000

Ms. D. Mooka
P.O. Box 479
GABORONE

Dear Madam,

REF: GRANT OF A RESEARCH PERMIT: MS. P. MOOKA

Your application for a permit refers.

We are pleased to inform you that you have been granted permission to carry out a study entitled "Examining Home Care of Chronically/Terminally, ill Persons by Family Caregivers and their Interaction with Health Care Providers". The study will be conducted at Kweneng District.

The permit is valid for a period not exceeding one (1) year effective September 27, 2000.

The permit is granted subject to the following conditions.

- 1., Copies of any papers written as a result of the study are directly deposited with the Office of the President, National Assembly, Ministry of Health, National Conservation Strategy Agency, National Archives, National Library Service, National Institute for Research and University of Botswana Library.
2. You conduct the study according to the particulars furnished in the application.
3. You include a questionnaire in your protocol and refine your protocol to ensure that the objectives of the study are addressed.
4. You justify why the study is undertaken and the hypothesis tested.

The permit does not give authority to enter any premises, private establishment or protected area. Permission for such entry should be negotiated with those concerned.

Yours faithfully.



J. Mosweu

for/PERMANENT SECRETARY TO THE PRESIDENT

Permanent Secretary, Ministry of Health
Clerk of the National Assembly
Executive Secretary, National Conservation Strategy Agency
Director, National Archives
Director, National Library Service
Director, National Institute for Research
Librarian, University of Botswana Library
District Commissioner, Molepolole
Council Secretary, Moiepolole
Landboard Secretary, Molepolole

6L=?HONE: 320111/248
CLEGRAMS." DISCCM
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OFFICE OF THE DISTRICT COMMISSIONER
PRIVATE BAG 3
MOLEPOLOLE
BOTSWANA

REF:KDDA/A23.5111(141)

REPUBLIC OF BOTSWANA

12 Sept. 2000

Mrs Dorothy Mooka
I H S
P. O. Box 684
Molepolole

Dear Madam

PERMISSION TO CONDUCT RESEARCH

We refer to your letter dated 16 August, 2000 which deals with your request for permission to conduct research in Molepolole.

We would like you to direct your application to the Office of the President.

Thank you.

Yours faithfully

A handwritten signature in black ink, appearing to be 'T. G. Molefe'.

T. G. Molefe
For/DISTRICT COMMISSIONER

TELEPHONE:

TELEGRAMS: N G A K A

REFERENCE:

SLH 10/! 29 1(9)



REPUBLIC OF BOTSWANA

SCOTTISH LIVINGSTONE HOSPITAL

PRIVATE BAG 001

MOLEPOLOLE

24th August 2000

Dorothy Mooka
Institute of Health Sciences
Box 684
Molepolole

Dear Sir/Madam,

RE: CONDUCTING RESEARCH IN SCOTTISH LIVINGSTONE HOSPITAL

Your request to conduct a research on "HOME CARE FOR THE CHRONICALLY' TERMINALY ILL PERSONS AND THEIR INTERACTION WITH THE HEALTH CARE PROVIDERS" in Scottish Livingstone Hospital is hereby granted on condition that it will not unduly interfere with smooth running of the facility is as far as health service/provision is concerned.

Wishing you success in your research.

Yours faithfully

A handwritten signature in black ink, appearing to read 'J. O. Orega'.

/ Dr J. O. Orega
CHIEF MEDICAL OFFICER

- Annexure 4 Patient interview guide**
- Annexure 5 Family care giver interview guide**
- Annexure 6 Family care giver interview guide**

10. Accommodation

How many rooms are in this household?_
How many people live in this household?_
How many people share a room?_
How many people need care in this household?_

U. Is the accommodation adequate for home care nursing? Yes_____No

Comments

Discharge Planning

12. How long were you in hospital before your initial discharge^

13. Did you feel ready to come home? Yes_____No.

Comments

14 Who discussed your illness with you on discharge?

Medical Doctor_
Nurse_
Social Welfare worker_
No one_
other (specify)_

15. Do you have a particular problem coping with your illness⁰

Yes_____No_

Comments

Self Care

16. Do you have a particular problem coping with care?

Yes_____No_

Comments

17. Do you have any other problem?
 Yes _____ No

Comments

Patients Needs

13. Please indicate the level to which you feel the your needs are being met by family care givers. (SA = strongly agree, A " Agree, N ~ Neutral, DA ` Disagree, SD = Strongly Disagree)

	5 0	OA	N	A	SA
j a. Comfort, sleep & cleanliness					
b. Administration of medications					
, c. Spiritual support provided					
d. Predictable and orderly environment					
e. Feeling of security and safety					
f. Love and affection from significant others					
g. Acceptance by family members					
h. Communicating relationship with significant others					
i. Feeling of self reliance					
j. Feeling of usefulness					
k. Feeling of independence					
I. Unity with loved ones					
m. Appreciation from others					
n. Dignity preserved					
o. Acceptance of my condition					
p. Involvement in decision about own health					
' q. Knowing about my illness and treatment					
r. Felling of self worthy					
s. Fear of dying					
• t. Assistance with care or help with equipment					
u. Assistance with counseling about personal hygiene					
v. Finance & family ability to provide care					
w. Quality of health teaching					
x. Quality of supervision in home care					

20. Indicate your level of satisfaction with home care in relation to health service providers
 (VD = Very Dissatisfied, D = Dissatisfied, U = Unsure, S = Satisfied, VS = Very Satisfied)

	VD	D	U	S	VS
a. Dependability of health staff					
b. Consistency of persons visiting home					
c. frequency of home visits					
d. Promptness of response to call by health workers					
e. No of home visits					
f. Quality of service					
g. Assistance from others in caring for you					

21. What resources do you need, but do not have for self care?

22. Do you know where to get assistance with the needed resources in question 21.
 Yes No

If yes, where?

CARE GIVER

Care giver interview guide

Please respond to all questions by making a tick (✓) against items that best represent your response or through comments where appropriate.

1. Ward Bokaa _____ Borakanelo _____ Boribama _____
 Kgosing _____ Mcc _____

2. Please indicate your sex Male _____ Female _____

3. Please indicate your age category
 0-9 yrs _____ 41-50 yrs _____
 10-20 yrs _____ 51-60 yrs _____
 21-40 yrs _____ 61+ yrs _____

4. Please indicate your marital status
 Single _____ Married _____ Separated _____
 Widowed _____ Divorced _____ Cohabiting _____

5. What is your highest level of education?
 None _____ Non formal _____
 Primary _____ Secondary _____
 Tertiary (specify) _____

6. Do you have a job?
 Yes _____ No _____

7. What type of employment do you have?
 Government employee _____
 NGO employee _____
 Not employed _____
 Other (specify) _____

8. What is your monthly income
 P0 - 200 _____
 P201 - 400 _____
 P401 - 600 _____
 P601 - 800 _____
 P801 - P1000 _____
 P1000 and above _____

9. If unemployed what is your source of income?

10. What is your relationship to the patient?

Mother_____Father_____Spouse_____Sibling_
Child_____In law_____Friend_____Relative_
Other (specify)_____

11. How long have you been giving health care to an ill relative ?

0 - 5 yrs_
6 - 10 yrs_
11 - 15 yrs_

Discharge Planning

12. Was the patients diagnosis disclosed to you"

Yes_____No_____ "

13. Have you been trained to care for the patient by the health worker before the patient was discharged from the hospital"⁷

Yes_____No_

14. IfNo, who trained you?

15. Was your health status assessed by a health provider before taking up care giving?

Yes_____No_

16 how do you rate your health?

Poor	Fair	Good	Very good	Excellent

17. Do you have any chronic illness?

Yes_____No_

Care giving

18. Do you feel confident to care for the patient?

Yes_____No_

Comments:

19. Do you have any particular problems coping with providing care for the patient at home^{1*}

Yes_____No_

If yes, Specify

20. Has care giving affected your physical health?
If yes, how_

21. Has care giving affected your social life⁰ Yes_____No
If yes, how_

22. Indicate how much family members participate in care of patient⁰

Never	1	3 a re ly	O Hen	Al ways
				1

23. Describe your coping and survival strategies while caring for the chronically/terminally ill person.

24. Would you recommend home care for another person?
Yes_____No_

Comments

25. How often do health care providers involve you in the decision making process about patient care?

Never	H a re ly	o ften	A l w a y s

Comments

26. Indicate how frequent the home visits from health workers are?

3 times a week	Once a week	Once a month	Once in 6 months	less than 6 months
				1

Other specify

Resources

27. What resources do you need, but do not have, for providing, in order to provide proper care to the patient?

28. Do you know who to ask for assistance with the needed resources listed in the above question?

Yes _____ No _____

If Yes, Who?

29. Indicate which health care provider is easily available?

Nurse	Social worker	Family welfare Educator	Doctor

Other (Specify) _____

30. Indicate your level of satisfaction with home care in relation to health service providers.
(SA = strongly agree, A = Agree, N = Neutral, DA = Disagree, SD = Strongly Disagree)

- a. Dependability of health staff
- b. Consistency of persons visiting home
- c. Frequency of home visits
- d. Promptness of response of Care giver/patient to call
- e. Number of home visits
- f. Quality of services
- g. Assistance from others in caring for the patient

	VD	D	U	S	VS
a. Dependability of health staff					
b. Consistency of persons visiting home					
c. Frequency of home visits					
d. Promptness of response of Care giver/patient to call					
e. Number of home visits					
f. Quality of services					
g. Assistance from others in caring for the patient					

Care giving needs

31. Please indicate the extent you agree/disagree with the following statements.
 (SA = Strongly Agree, A = Agree, N = Neutral, DA = Disagree, SD = Strongly Disagree)
 My needs as a caregiver were met in the following areas >

	S D	DA	N	A	SA
i. health needs status assessed before adopting care giving role		1			
ii. Physical assistance with patients hygiene					
iii. Encouraged to express fear & concerns					
iv. Administrations of medications					
v. Spiritual support					
vi. Counseling					
vii. Provision of physiologic needs of supplies (food, sleep, medical, sexuality, clothing etc.)					
viii. Time to listen to my concerns					
ix. Training in care giving before patient was discharged from hospital by a health care provider					
x. Input into decision making					
xi. Close confiding relationship					
xii. Tangible assistance during time of crisis provided					
xiii. Provide feelings of personal affection					
xiv. Opportunity to relate meaningfully to others					
xv. Comfort and cleanliness in the home					
xvi. Predictable orderly environment					
xvii. Love and affection from significant others					
xviii. Acceptance of caring role					
xix. Approval of loved ones					
xx. Self reliance					
xxi. Mastery and competence in caring skills					
xxii. Independence					
xxiii. Encouraged to express perceptions about patients illness					
xxiv. family members participate in care giving ¹					
xxv. Information and education about clients illness					
xxvi. care of other dependents					
xxvii. Household tasks					
xxviii. Transportation					
xxix. Shopping					
xxx. Quality of health teaching					
xxxi. Quality of supervision					

Comments

Accessibility of Services

32. Please indicate if the health care provider facilitated accessibility of the following services by answer Yes or Not to the following questions :-

	Service Needed	Told about	Provided access
	Yes/No	Yes/No	Yes/No
a. Availability of support systems			
- family support			
- Peer support			
- Religious support			
- Voluntary organization support			
b. Social Welfare services			
- Famine relief services			
- Destitute programme			
- Orphans programme			
- Food, clothing, blankets			
c. Availability of community services			
- Cancer association			
- Diabetic association			
- Hospice association			
- Home aid services			
- Rehabilitative services			
- Respite (child care services)			
- Special health education services			
- Home visiting programmes			
- Treatment centers			
d. Transport			
e. Finance			
f. Medical supplies e.g. bandages, gloves etc.			
g. Shelter (housing)			
h. Referral to appropriate agencies			

Comments

HEALTH CARE PROVIDERS INTERVIEW GUIDE

Please respond to all questions by either placing a tick (✓) in the spaces provided or through comments where necessary.

Demographic data

1. Health facility_
2. Catchment area_
3. What is your occupation?
 Medical Doctor_____Nurse_____Social Welfare_
 Family Welfare Educator_____Other(Specify)_

Health Care Resources

4. To what extent are your patients able to utilize available resources on home based care⁹

Never	Sometimes	Always	Don't know
1			

Comments

5. To what extent are the family care givers you serve able to utilize available resources on home based care?

Never	Sometimes	Always	Don't know
			1

Comments

6. What contributes to under utilization of home care resources in your catchment area⁰

Don't know	Lack of information	Culture/Tradition	Indifference
1			

Comments

7. What is your role in the acquisition of community resources by clients on home based care?

- Coordinator_____Consultant_
 Collaborator_____Delegating_
 Other (Specify)_

Care Giving

8. How would you rate the quality of home care amongst the families you are working with?

Poor	Fair	Good	Very good	Excellent

Why? _____

9. Indicate how much you agree/disagree.
 (SA = Strongly agree, A = Agree, N = Neutral, DA = Disagree, SD = Strongly disagree)
 Patients should be re-admitted when:-

- a. Family care giver is no longer able to manage
- b. Primary diagnosis becomes worse
- c. Doctor requests re-admission
- d. Supplies are inadequate at home
- e. Care giver does not want the responsibility any longer

SD	DA	N	A	SA

Comments _____

10. Please rate the level of family participation in the care of patients in the community or catchment area in which you are serving by placing a tick (✓) in the column below.

Poor	Fair	Good	Very good	Excellent

11. Indicate the patients' ability to negotiate treatment with health care providers.

Poor	Fair	Good	Very good	Excellent

12. Indicate the family care givers' ability to negotiate treatment with health care providers.

Poor	Fair	Good	Very good	Excellent

13. Is quality care accessible to all individuals needing home based care in your catchment area?
 Yes No

[fNo, Why¹

Care Giving

8. How would you rate the quality of home care amongst the families you are working with⁰

Poor	Fair	Good	Very good	Excellent

Why⁰

9. Indicate how much you agree/disagree.

(SA = Strongly agree, A = Agree, N - Neutral, DA = Disagree, SD = Strongly disagree)

Patients should be re-admitted when:-

- a. Family care giver is no longer able to manage
- b. Primary diagnosis becomes worse
- c. Doctor requests re-admission
- d. Supplies are inadequate at home
- e. Care giver does not want the responsibility any longer

SD	DA	N	A	SA

Comments

10. Please rate the level of family participation in the care of patients in the community or catchment area in which you are serving by placing a tick (S) in the column below.

Poor	Fair	Good	Very good	Excellent

11. Indicate the patients' ability to negotiate treatment with health care providers.

Poor	Fair	Good	Very good	Excellent

12. Indicate the family care givers' ability to negotiate treatment with health care providers.

Poor	Fair	Good	Very good	Excellent

13. Is quality care accessible to all individuals needing home based care in your catchment area⁰

Yes No

[If No, Why⁰

14. What is your role in the follow up of discharged patients?

Coordinator _____ Consultant _____ Collaborator _____
Delegating _____ Mentoring _____
Other (Specify) _____

Needed health Services

15. Are Needed health Services accessible to all care givers?

Yes _____ No _____

If No, which services are not accessible and why?

16. How would you rate the amount of time you have been given for home visits?

Poor	Fair	Good	Very good	Excellent

Comments

Level of Satisfaction

17. Indicate the level of satisfaction with home care in relation to health service providers.

- a. Dependability of health staff
- b. Consistency of persons visiting home
- c. Frequency of home visits
- d. promptness of response to call by patient/care giver
- e. Number of home visits
- f. Quality of services
- g. Assistance from others in caring for the patient

Poor	Fair	Good	Very good	Excellent

Comments _____

Annexure 7 Research questions

Annexure 7

Research Questions	Questions from instrument			Statistics
	Patient	Family care giver	Family care giver	
1. Are the needs of chronically/terminally ill patients being met by family care givers and professional health care providers?	18-19			Central tendency-SD
2. Are the needs of family care givers being met?		31		Central tendency
3. Is there a relationship between the health workers attitudes toward chronically/terminally ill persons and their years of experience as health workers?			18	Central tendency Pearson/Correlation
4. What type of support is given to family care givers of chronically/terminally ill persons by health care providers?		12-15, 18-19, 29, 32		Central tendency Cross-Tab
5. Is there a difference between patients, family care givers and health care providers level of satisfaction with home care relative to the service provided?				ANOVA/ T-test Central tendency
6. What are patients, family care givers and health care providers perception of home based care relative to the actual care given, acquisition and utilization of resources				Central tendency
Demographic data	1-11	1-11 16-17	1-3	Central tendency -Means -Median -Mode

Frequencies

Frequency Table

Ward

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Bokaa	5	20.0	20.0	20.0
	Borakanelo	5	20.0	20.0	40.0
	Boribamo	5	20.0	20.0	60.0
	Kgosing	5	20.0	20.0	80.0
	Mcc	5	20.0	20.0	100.0
	Total	25	100.0	100.0	

Gender of respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	2	8.0	14.3	14.3
	Female	12	48.0	85.7	100.0
	Total	14	56.0	100.0	
Missing	System	11	44.0		
Total		25	100.0		

Age of respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	10 to 20 years	1	4.0	4.2	4.2
	21 to 40 years	9	36.0	37.5	41.7
	41 to 50 years	6	24.0	25.0	66.7
	51 to 60 years	3	12.0	12.5	79.2
	61 and over	5	20.0	20.8	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

Marital status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	single	17	68.0	70.8	70.8
	married	3	12.0	12.5	83.3
	widowed	4	16.0	16.7	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

What is your highest level of education?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	non-formal	1	4.0	4.0	4.0
	primary	11	44.0	44.0	48.0
	secondary	6	24.0	24.0	72.0
	none	7	28.0	28.0	100.0
	Total	25	100.0	100.0	

What is your employment status?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not employed	19	76.0	86.4	86.4
	self employed	1	4.0	4.5	90.9
	domestic worker	2	8.0	9.1	100.0
	Total	22	88.0	100.0	
Missing	System	3	12.0		
Total		25	100.0		

What is your monthly income?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 200	19	76.0	82.6	82.6
	201 to 400	1	4.0	4.3	87.0
	401 to 600	1	4.0	4.3	91.3
	none	2	8.0	8.7	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

Is your income adequate in meeting your needs?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	3	12.0	13.0	13.0
	no	20	80.0	87.0	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

Is this accomodation adequate for home care nursing?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	17	68.0	70.8	70.8
	no	7	28.0	29.2	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

How long were you in hospital before your initial discharge?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	7	28.0	43.8	43.8
	2	4	16.0	25.0	68.8
	3	2	8.0	12.5	81.3
	never been admitted	3	12.0	18.8	100.0
	Total	16	64.0	100.0	
Missing	System	9	36.0		
Total		25	100.0		

Did you feel ready to come home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	9	36.0	36.0	36.0
	no	13	52.0	52.0	88.0
	not applicable	3	12.0	12.0	100.0
	Total	25	100.0	100.0	

Who discussed your illness with you on discharge?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	medical doctor	9	36.0	37.5	37.5
	nurse	9	36.0	37.5	75.0
	social welfare worker	1	4.0	4.2	79.2
	no one	4	16.0	16.7	95.8
	family welfare educator	1	4.0	4.2	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

Do you have a particular problem coping with your illness?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	10	40.0	43.5	43.5
	no	12	48.0	52.2	95.7
	99	1	4.0	4.3	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

Do you have a particular problem coping with care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	52.0	56.5	56.5
	no	9	36.0	39.1	95.7
	99	1	4.0	4.3	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

Do you have any other problem?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	52.0	59.1	59.1
	no	9	36.0	40.9	100.0
	Total	22	88.0	100.0	
Missing	System	3	12.0		
Total		25	100.0		

comfort, sleep and cleanliness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.2	4.2
	disagree	3	12.0	12.5	16.7
	agree	15	60.0	62.5	79.2
	strongly agree	5	20.0	20.8	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

administration of medications

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.2	4.2
	disagree	1	4.0	4.2	8.3
	neutral	3	12.0	12.5	20.8
	agree	19	76.0	79.2	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

spiritual support provided

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.3	4.3
	disagree	3	12.0	13.0	17.4
	neutral	7	28.0	30.4	47.8
	agree	12	48.0	52.2	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

predictable and orderly environment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.0	4.0
	disagree	5	20.0	20.0	24.0
	neutral	1	4.0	4.0	28.0
	agree	16	64.0	64.0	92.0
	strongly agree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

feeling of security and safety

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.2	4.2
	disagree	5	20.0	20.8	25.0
	neutral	1	4.0	4.2	29.2
	agree	15	60.0	62.5	91.7
	strongly agree	2	8.0	8.3	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

love and affection from significant others

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.0	4.0
	disagree	3	12.0	12.0	16.0
	neutral	2	8.0	8.0	24.0
	agree	15	60.0	60.0	84.0
	strongly agree	4	16.0	16.0	100.0
	Total	25	100.0	100.0	

acceptance by family members

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.2	4.2
	disagree	4	16.0	16.7	20.8
	neutral	2	8.0	8.3	29.2
	agree	13	52.0	54.2	83.3
	strongly agree	4	16.0	16.7	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

communicating relationship with significant others

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.3	8.3
	disagree	4	16.0	16.7	25.0
	neutral	1	4.0	4.2	29.2
	agree	14	56.0	58.3	87.5
	strongly agree	3	12.0	12.5	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

feeling of self reliance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.0	4.0
	disagree	9	36.0	36.0	40.0
	neutral	1	4.0	4.0	44.0
	agree	11	44.0	44.0	88.0
	strongly agree	3	12.0	12.0	100.0
	Total	25	100.0	100.0	

feeling of usefulness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.0	8.0
	disagree	10	40.0	40.0	48.0
	neutral	1	4.0	4.0	52.0
	agree	10	40.0	40.0	92.0
	strongly agree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

feeling of independence

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	disagree	11	44.0	44.0	44.0
	neutral	2	8.0	8.0	52.0
	agree	11	44.0	44.0	96.0
	strongly agree	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

unity with loved ones

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	disagree	5	20.0	20.0	20.0
	neutral	6	24.0	24.0	44.0
	agree	12	48.0	48.0	92.0
	strongly agree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

appreciation from others

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	disagree	3	12.0	12.5	12.5
	neutral	7	28.0	29.2	41.7
	agree	12	48.0	50.0	91.7
	strongly agree	2	8.0	8.3	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

dignity preserved

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.0	8.0
	disagree	5	20.0	20.0	28.0
	neutral	9	36.0	36.0	64.0
	agree	8	32.0	32.0	96.0
	strongly agree	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

acceptance of my condition

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	4	16.0	16.0	16.0
	disagree	6	24.0	24.0	40.0
	neutral	4	16.0	16.0	56.0
	agree	9	36.0	36.0	92.0
	strongly agree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

involvement in decision about own health

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	3	12.0	12.0	12.0
	disagree	6	24.0	24.0	36.0
	neutral	8	32.0	32.0	68.0
	agree	8	32.0	32.0	100.0
	Total	25	100.0	100.0	

knowing about my illness and treatment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	5	20.0	20.0	20.0
	disagree	6	24.0	24.0	44.0
	neutral	6	24.0	24.0	68.0
	agree	8	32.0	32.0	100.0
	Total	25	100.0	100.0	

feeling of self worthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	6	24.0	24.0	24.0
	disagree	7	28.0	28.0	52.0
	neutral	5	20.0	20.0	72.0
	agree	7	28.0	28.0	100.0
	Total	25	100.0	100.0	

fear of dying

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.0	8.0
	disagree	10	40.0	40.0	48.0
	neutral	7	28.0	28.0	76.0
	agree	6	24.0	24.0	100.0
	Total	25	100.0	100.0	

assistance with care or help with equipment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	1	4.0	4.3	4.3
	disagree	8	32.0	34.8	39.1
	neutral	9	36.0	39.1	78.3
	agree	5	20.0	21.7	100.0
	Total	23	92.0	100.0	
Missing	System	2	8.0		
Total		25	100.0		

assistance with counseling about personal hygiene

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	4	16.0	16.0	16.0
	disagree	11	44.0	44.0	60.0
	neutral	4	16.0	16.0	76.0
	agree	6	24.0	24.0	100.0
	Total	25	100.0	100.0	

finance and family ability to provide care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	5	20.0	20.0	20.0
	disagree	8	32.0	32.0	52.0
	neutral	5	20.0	20.0	72.0
	agree	7	28.0	28.0	100.0
	Total	25	100.0	100.0	

quality of health teaching

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	4	16.0	16.0	16.0
	disagree	10	40.0	40.0	56.0
	neutral	7	28.0	28.0	84.0
	agree	4	16.0	16.0	100.0
	Total	25	100.0	100.0	

quality of supervision in home care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	4	16.0	16.7	16.7
	disagree	9	36.0	37.5	54.2
	neutral	7	28.0	29.2	83.3
	agree	4	16.0	16.7	100.0
	Total	24	96.0	100.0	
Missing	System	1	4.0		
Total		25	100.0		

comfort, sleep and cleanliness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	4	16.0	16.0	16.0
	disagree	14	56.0	56.0	72.0
	neutral	3	12.0	12.0	84.0
	agree	4	16.0	16.0	100.0
	Total	25	100.0	100.0	

administration of medications

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.0	8.0
	disagree	9	36.0	36.0	44.0
	agree	14	56.0	56.0	100.0
	Total	25	100.0	100.0	

spiritual support provided

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly disagree	2	8.0	8.0	8.0
	disagree	6	24.0	24.0	32.0
	neutral	15	60.0	60.0	92.0
	agree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

predictable and orderly environment

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	3	12.0	12.5	12.5
disagree	9	36.0	37.5	50.0
neutral	5	20.0	20.8	70.8
agree	6	24.0	25.0	95.8
strongly agree	1	4.0	4.2	100.0
Total	24	96.0	100.0	
Missing System	1	4.0		
1 Total	25	100.0		

feeling of security and safety

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.0	8.0
disagree	13	52.0	52.0	60.0
neutral	4	16.0	16.0	76.0
agree	5	20.0	20.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	

love and affection from significant others

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.0	8.0
disagree	9	36.0	36.0	44.0
neutral	5	20.0	20.0	64.0
agree	8	32.0	32.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	

acceptance by family members

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	1	4.0	4.0	4.0
disagree	9	36.0	36.0	40.0
neutral	3	12.0	12.0	52.0
agree	11	44.0	44.0	96.0
strongly agree	.1	4.0	4.0	100.0
Total	25	100.0	100.0	

communicating relationship with significant others

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	1	4.0	4.0	4.0
disagree	9	36.0	36.0	40.0
neutral	4	16.0	16.0	56.0
agree	10	40.0	40.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	

feeling of self reliance

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.7	8.7
disagree	10	40.0	43.5	52.2
neutral	4	16.0	17.4	69.6
agree	7	28.0	30.4	100.0
Total	23	92.0	100.0	
Missing System	2	8.0		
Total	25	100.0		

feeling of usefulness

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.3	8.3
disagree	11	44.0	45.8	54.2
neutral	3	12.0	12.5	66.7
agree	8	32.0	33.3	100.0
Total	24	96.0	100.0	
Missing System	1	4.0		
Total	25	100.0		

feeling of independence

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.0	8.0
disagree	10	40.0	40.0	48.0
neutral	8	32.0	32.0	80.0
agree	5	20.0	20.0	100.0
Total	25	100.0	100.0	

unity with loved ones

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	1	4.0	4.0	4.0
disagree	11	44.0	44.0	48.0
neutral	4	16.0	16.0	64.0
agree	8	32.0	32.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	

appreciation from others

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	3	12.0	12.0	12.0
disagree	9	36.0	36.0	48.0
neutral	5	20.0	20.0	68.0
agree	8	32.0	32.0	100.0
Total	25	100.0	100.0	

dignity preserved

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.0	8.0
disagree	8	32.0	32.0	40.0
neutral	5	20.0	20.0	60.0
agree	10	40.0	40.0	100.0
Total	25	100.0	100.0	

acceptance of my condition

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	2	8.0	8.0	8.0
disagree	7	28.0	28.0	36.0
neutral	9	36.0	36.0	72.0
agree	6	24.0	24.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	

involvement in decision about own health

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly disagree	5	20.0	20.0	20.0
disagree	3	12.0	12.0	32.0
neutral	14	56.0	56.0	88.0
agree	2	8.0	8.0	96.0
strongly agree	1	4.0	4.0	100.0
Total	25	100.0	100.0	